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A RURAL-URBAN COMPARISON OF SELF-MANAGEMENT IN PEOPLE AFFECTED BY CANCER FOLLOWING TREATMENT: A MIXED METHODS STUDY

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ABSTRACT

Background: People affected by cancer have to self-manage the consequences of cancer long after primary treatment has ended. In cancer survivorship, self-management has been defined as awareness and active participation by the individual in their recovery, recuperation and rehabilitation to minimise the consequences of treatment, and promote survival, health and wellbeing (DH, Macmillan Cancer Support and NHS Improvement, 2010).

Despite a significant drive towards promoting and supporting self-management with people affected by cancer there is a lack of research examining whether residence (rural-urban) has an influence on self-management following cancer treatment. The primary aim of this thesis was to investigate and compare self-management, in people affected by cancer following treatment from rural and urban areas.

Methods: The study utilised a cross-sectional mixed methods design that incorporated both quantitative and qualitative methods of data collection.

Firstly, this involved a self-completion postal questionnaire (N=227) that collected quantitative data on demographics, rural-urban residence, health status, health-promoting behaviours, patient activation, cancer-related self-efficacy and qualitative free-text information on self-management behaviours. This was followed by a series of in-depth qualitative interviews (N=34) that aimed to identify, and compare the barriers and facilitators to self-management in people affected by cancer from rural and urban settings in the East Midlands of England. Both datasets were integrated to further explain the quantitative differences that were identified between rural and urban participants.

Results: Participants from rural areas reported higher scores across a range of quantitative variables, indicative of greater levels of engagement with health promoting behaviours and self-management compared to those from urban areas. Specifically, rural participants scored higher with regard to health responsibility ($p<0.01$; nutrition ($p<0.001$); spiritual growth ($p<0.01$); and interpersonal relationships ($p<0.001$). Rural respondents (63.31±13.66) had higher patient activation than those in urban areas (59.59±12.75) although this was not statistically significant at $p<0.01$. Those residing in rural areas (7.86±1.70) had significantly ($p<0.01$) greater cancer-related self-efficacy compared to those in urban areas (7.09±1.96). Rural respondents had significantly higher self-efficacy than urban respondents with regard to confidence to manage physical discomfort ($p<0.01$), emotional distress ($p<0.001$), and to

contact their doctor about problems caused by cancer ($p<0.01$). The findings from the multivariate analysis highlighted that rural-urban residence was not a significant predictor of health-promoting behaviours, patient activation or cancer-related self-efficacy when adjusting for living arrangement, marital status, qualifications and self-reported health status. Self-reported health status proved to be a significant predictor on all three outcomes when controlling for confounders.

Three themes were identified in the qualitative data which related to barriers that prevented participants from engaging with self-management: (1) Location (2) Relationship Based and (3) Personal. In relation to facilitators that enhanced participants' active participation in their recovery, three subthemes were identified: (1) Effective Communication and Information; (2) Informal and Peer Support and (3) Motivation. The barriers and facilitators that were identified were prevalent in both the rural and urban setting. However, some aspects belonging to these barriers and facilitators were more explicit in the rural or urban environment. For example, there was a lack of bespoke support in rural areas and participants acknowledged how traveling long distances to urban centres for support groups was problematic. Motivation to engage with self-management was not unique and both sets of participants were motivated by a desire to be healthy and take part in group activities and sports. Although rural participants did have easier access to greenspaces and community activities, which could enhance motivation further.

Conclusion: The quantitative findings highlighted that people in rural areas were more engaged with health-promoting behaviours and better at self-managing their health compared to those in urban areas. The majority of the barriers and facilitators that were identified were not necessarily unique to the urban or rural environment. Certainly, the qualitative data show that residency is not as unequivocal as the quantitative results would suggest. However, engagement with the local community was greater in rural areas which could account for the differences.

Whilst the active treatment phase can present considerable challenges for people affected by cancer in rural areas the findings suggest that the rural environment has the potential to increase engagement with self-management in the transition to survivorship.

LAY SUMMARY

There are an increasing number of people living with and beyond cancer who are having to self-manage the consequences of cancer long after treatment had ended. Self-management refers to how aware and active people are in their recovery as well as behaviours that they engage with to promote health and wellbeing. To date, there is no research that has examined the role of rural-urban residency in relation to self-management following cancer treatment.

The research involved a questionnaire and a series of one-to-one interviews. 227 people completed a questionnaire that asked them about their engagement with a range of health-promoting behaviours as well as their knowledge, skills and confidence to self-manage. The findings were compared between rural and urban participants. 34 people took part in an interview that aimed to understand what helped or prevented them from self-managing their health and healthcare following cancer treatment.

The findings highlighted that people in rural areas were more engaged with health-promoting behaviours and better at self-managing their health compared to those in urban areas. The interviews found that informal support positively influenced recovery and self-management, although support and involvement with the local community was greater in rural areas which could account for the differences.

Key words: self-management; cancer survivorship; health behaviours; patient activation; self-efficacy; rural-urban research; mixed methods**.**

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CHAPTER ONE: INTRODUCTION

1.1 Introduction to Chapter

This thesis reports on the findings from a study that investigated and compared self-management in people affected by cancer who were post-treatment from both rural and urban settings. The research was undertaken for the award of a doctoral degree within the School of Health and Social Care at the University of Lincoln, UK.

The research utilised a cross-sectional mixed methods design that incorporated both quantitative and qualitative methods of data collection (Chapter 4). Firstly, this involved a self-completion postal questionnaire (N=227) that collected quantitative data on health-promoting behaviours, patient activation, cancer-related self-efficacy and qualitative free-text information on self-management. The results of which are reported on in Chapter 5. This was then followed up with a series of in-depth qualitative interviews (N=34) that aimed to identify, and compare the barriers and facilitators to self-management in people affected by cancer from rural and urban settings. The results from the interviews can be found in Chapter 6. The quantitative results were used to inform the characteristics of participants that were purposively selected for the qualitative interviews. The results were analysed separately and integrated in the discussion section of this thesis (Chapter 7).

This chapter begins by presenting the contextual background to the study in relation to the wider cancer survivorship and self-management literature. Following this, the importance of the research and its contribution to knowledge are reported on in addition to the rationale for the study. Subsequently, the aims and objectives of the research are introduced, as well as the primary research question that the thesis aimed to answer. This is succeeded by an overview of how the study was monitored and the role of the Project Steering Group in overseeing and supporting the research. Finally, the thesis structure and contents of the subsequent chapters that follow are provided, as well as, a summary of this chapter.

1.2 Aims and Objectives

According to Rojon and Saunders (2012) research is concerned with systematically collecting and analysing data to increase our understanding about a topic of interest and in this thesis, that topic was self-management in people affected by cancer from rural and urban areas. Throughout this research process, the researcher was trying to answer a question or address a problem, which is routinely referred to as 'meeting the research aim' or 'addressing the research objectives' (Rojon and Saunders, 2012). Therefore, there was a requirement to formulate a clear set of aims, objectives and research questions to justify and contextualise the study.

The primary aim of this thesis was: **To investigate and compare self-management in people affected by cancer following treatment from rural and urban areas.**

Consequently, the research sought to provide a comprehensive answer to the below primary research question: **What are the differences in self-management in people affected by cancer following treatment from rural and urban areas?**

There were a number of sub-research questions that were formulated following the literature review (see Chapter 2) that identified a gap in the existing cancer survivorship literature, particularly, a dearth of research on rural-urban residency and whether this influenced self-management after cancer treatment. These sub-questions warranted both quantitative and qualitative methods of inquiry whilst still aiming to answer the primary research question that was outlined above. These sub-questions are reported on in further detail in the methodology chapter of this thesis (see Chapter 3: 3.2 Research Question(s)).

Finally, the following research objectives were derived to facilitate the achievement of the above primary research aim:

- *Objective One:* To conduct a scoping review of the literature in relation to cancer survivorship, self-management and rural-urban residency.

- *Objective Two:* To identify a range of quantitative outcome measures from the existing literature that can be used to measure self-management in people affected by cancer from rural and urban areas.

- *Objective Three:* To establish a professional network at two NHS Trusts to support and facilitate recruitment of potential participants.

- *Objective Four:* To design and disseminate a questionnaire that collected data on the identified quantitative outcome measures.

- *Objective Five:* To establish a Patient and Public Involvement (PPI) group to pilot research materials prior to seeking ethical approval and data collection.

- *Objective Six:* To seek and obtain ethical and research governance approval from the appropriate bodies prior to data collection.

- *Objective Seven:* To analyse the quantitative data and write up the results in the form of a thesis chapter.

- *Objective Eight:* To recruit a sample of people affected by cancer from rural and urban areas to take part in a qualitative in-depth interview.

- *Objective Nine:* To thematically analyse the qualitative interview data and write up the results in the form of a thesis chapter.

- Objective Ten: To integrate the quantitative and qualitative findings and write up in the form of a discussion chapter in this thesis.

- *Objective Eleven:* To provide a series of recommendations in terms of self-management support in rural and urban areas.

1.3 Background

By 2030, the global burden of cancer is expected to grow to 21.7 million new cases and thirteen million deaths per year (Ferlay et al, 2015). As such, cancer represents a global health problem and poses a significant threat to public health worldwide with incidence rates having increased in most countries since the 1990s (Global Burden of Disease Cancer Collaboration, 2015). In the UK alone, there are two and a half million people living with and beyond cancer and this is set to exceed five million by 2040 (Maddams et al, 2012). Furthermore, it is predicted that half of the people diagnosed with cancer in England and Wales in 2010-11 will survive for at least ten years, a rate which has doubled since the 1970s (Cancer Research UK, 2017), at the same time, with some cancers such as lung cancer, little has changed with survival remaining very poor. Conversely, in terms of breast and prostate cancer, the current ten-year survival rates in the UK are around seventy-eight per cent and eighty-four per cent respectively (Cancer Research UK, 2017). This can be attributed to a range of factors, such as, increases in the number of new diagnoses due to a growing and ageing population and improved survival as a result of advances in screening, earlier detection and improvements in and access to treatment (Calman and Foster, 2018; DeSantis et al, 2014).

Whilst increases in survival are a positive long-term outcome of improvements in care, they additionally present a range of challenges for the patient, their family, as well as the wider health and social care system. Indeed, this generates a growing population of older and younger adult cancer survivors many of whom have unmet survivorship needs (Parry et al, 2011) particularly at the end of treatment, such as psychological distress (Foster et al, 2009) and fear of recurrence (Armes et al, 2009) which can impact negatively on quality of life. Furthermore, some studies suggest that people with a diagnosis of cancer report more comorbid conditions and poorer physical and mental health compared to those without cancer (Smith et al, 2008) and they are more likely to suffer from fatigue (Corbett et al, 2016), anxiety (Greer et al, 2011), depression (Pasquini and Biondi, 2007), as well as, being at an increased risk of developing secondary tumours (Mariotto et al, 2007).

The increasing number of people living with and beyond cancer is putting significant pressure on the UK National Health Service (NHS) (Hawkes, 2015) and healthcare systems around the world are consistently trying to meet rising demand with limited resources. The literature suggests that the completion of cancer treatment through to what Mullan (1984) terms the 're-

entry' phase (medical and emotional issues of transition) and into long-term survivorship marks a difficult period of readjustment (Costanzo et al, 2007; Philip and Merluzzi, 2016). Thus, a considerable challenge now faced is to find new and innovative ways to treat, support and care for this emerging population after primary treatment ends (Rowland and Bellizzi, 2014) when they can have a range of complex medical and psychosocial needs. In recent decades, as a response to the growing number of people surviving cancer, Calman and Foster (2018) have noted an increasing focus on not just the quality of survival, but the number of disease-free years also. Nonetheless, it should not be assumed that just because an individual is 'disease free' that they are entirely cured of the consequences of a cancer diagnosis with some of the considerable and long-term impacts including emotional distress (Diemling et al, 2006), relationship and sexual problems (Badr and Carmack Taylor, 2009; Candy et al, 2016), as well as financial difficulties (Fenn et al, 2014; Foster et al, 2009; Marti et al, 2016). In some cases, the consequences of cancer can emerge five to ten years after treatment and these 'late effects' have a notable impact on individual health and wellbeing as well as everyday life (Calman and Foster, 2018). For example, some chemotherapy drugs can cause heart or lung problems later in life or even early menopause and infertility (Macmillan Cancer Support, 2018). Additionally, many people living with and beyond cancer may suffer from several other health problems that have been exacerbated or caused by a cancer diagnosis and its subsequent treatment (Edgington and Morgan, 2011).

Consequently, many people living with and beyond cancer are self-managing problems associated with cancer and its treatment (Foster and Fenlon, 2011) such as fatigue, pain, anxiety, and depression as part of their daily lives (Koornstra et al, 2014; Lovell et al, 2014; Yi and Syrjala, 2017). However, not everyone will have the support and information on how best to rehabilitate and actively engage with self-management (Smithson et al, 2012). Having said that, the majority of people living with and beyond cancer want to have an active role in their health care and to know how to self-manage their health as well as an awareness of what lifestyle changes they should make to promote health and wellbeing (Davies et al, 2011). The role of health-promoting behaviours, such as, adherence to a healthy diet and physical activity have been well researched with regards to cancer prevention and more recently in relation to cancer survivorship (Davies et al, 2011) where evidence suggests that lifestyle interventions can counter some of the adverse effects of treatment, prevent recurrence and reduce the risk of comorbid conditions (Jones and Denmark-Wahnefried, 2006; Pekmezi and Denmark-Wahnefried, 2011). For Lin (2016), the need for health promotion, might be even more salient

for people affected by cancer whose quality of life and capacity to live independently are frequently dependent on maintaining their health, which may be exacerbated by the consequences of a cancer diagnosis and treatment, or indeed other comorbid conditions.

The increase of cancer prevalence (Maddams et al, 2012) and evidence of unmet needs (Macmillan Cancer Support, 2015) means that the NHS is having to transform the ways in which it cares for people living with and affected by cancer. Thus, there is a need to shift away from an emphasis on acute and episodic care to a more holistic and personalised approach that is both coordinated and integrated (Macmillan Cancer Support, 2013). With that in mind, the Cancer Strategy (2015-20) put forward an ambitious five year vision for cancer care in England that was developed to make substantial progress in decreasing preventable cancers, increasing survival, supporting self-management and enhancing quality of life and patient experience (Independent Cancer Taskforce, 2015). A key component of this vision was to ensure that every person with a cancer diagnosis is offered and has access to a 'Recovery Package' (see Figure 1.1) which aims to address the longer-term physical, psychological and financial impacts of cancer (NHS England, 2017).

Figure 1.1 The Recovery Package

The Recovery Package was developed by the national charity, Macmillan Cancer Support (2013) and consists of several interventions, that when delivered together can significantly improve the health and wellbeing of people living with and beyond cancer in addition to supporting self-management. Firstly, it involves a Holistic Needs Assessment (HNA), at different points in the patient pathway. It can be offered at diagnosis, during treatment or post treatment and gives the individual affected by cancer a chance to discuss their concerns (physical, emotional, practical, financial and spiritual) and to consider potential solutions to their identified needs with the support of a key worker that is often a Clinical Nurse Specialist (CNS) (Macmillan Cancer Support, 2017). Next, it is recommended that a Treatment Summary is produced at the end of each acute phase of treatment that is then sent to both the patient and their GP. In sum, this is an overview of a patient's cancer diagnosis, treatment and ongoing management plan with the aim of improving communication between cancer services and primary care (Smith and Thompson, 2015). The Treatment Summary then aims to inform a subsequent Cancer Care Review (CCR) that is completed by a GP or Practice Nurse to discuss the individual's needs and it is recommended that this is carried out within six months of diagnosis (Macmillan Cancer Support, 2013). The CCR should be considered part of an ongoing process that improves follow up care by improving communication between primary and secondary care where people are empowered to self-manage with good primary care support and ready access to secondary care, if and when necessary (Smith and Thompson, 2015). Finally, Health and Wellbeing Events are a key component of the Recovery Package that support people affected by cancer through education and information provision. They help people living with and affected by cancer to take control and participate in their short and long-term recovery by giving them appropriate information and promoting positive lifestyle change and health behaviours (Macmillan Cancer Support, 2014). Indeed, individuals affected by cancer who want to engage with educational support should have the opportunity to attend Health and Wellbeing Events that prepare them for the transition to supported self-management. At the same time, this is not always the case as access to specialised support can be problematic, particularly in rural and remote areas (Buzza et al, 2011; Smith, 2012; Virani et al, 2011). Therefore, this is an area that needs attention if the ambitions of Macmillan and the Independent Cancer Taskforce (2015) are to be fulfilled in the years and decades to come.

Whilst the Recovery Package is still some way off being implemented consistently across the UK, early evidence from an economic evaluation (Macmillan Cancer Support, 2016) identified a range of impacts and benefits to both people affected by cancer and healthcare professionals.

For example, some benefits include decreased patient anxiety and improved patient and healthcare professional confidence, as well as, potential reduction in the use of acute care services. However, definitive conclusions are not yet possible without further data from across all of the UK. The successful provision of the Recovery Package is central to Macmillan achieving their nine patient-centred outcomes that by 2030, they hope will be applicable to all people living with a cancer diagnosis (see Figure 1.2).

Figure 1.2 Macmillan's Nine Outcomes for People Living with Cancer

Adapted from Macmillan Cancer Support (2014)

Despite this shift towards holistic and person-centred care that promotes health and wellbeing via initiatives such as the Recovery Package, there is a lack of research examining whether rural-urban residence has a significant bearing on self-management, adherence to health-promoting behaviours and recovery following treatment for cancer. This thesis aimed to address this substantial gap in the literature through a comprehensive analysis of a range of variables in relation to self-management with rural and urban populations.

1.4 Cancer Survivorship

The concept of 'survivorship', was first articulated by the physician and survivor of cancer Fitzhugh Mullan who maintained that once treated for cancer, the binary concept of "cured" or "not cured" did not appropriately represent the longer term experiences of cancer and that "survivorship" needed to be recognised as a phenomenon in its own right (Mullan, 1985). In his view, all individuals diagnosed with cancer had to cope with the physical and psychological effects of diagnosis and treatment, regardless of whether they were cured or not (Mullan, 1985). Therefore, Mullan was an advocate for the use of the term "survival", in that it was applicable to those who were both "cured" as well as those with ongoing disease (Feurstein, 2007).

In 1986, Mullan went on to become one of the founders of the American survivor led advocacy organisation, the National Coalition for Cancer Survivorship (NCCS) that sought to shift the focus from cancer 'victim' to cancer 'survivor' (Morgan, 2009). The NCSS supported the view that from the time of diagnosis and for the balance of life, an individual should be able to call themselves a 'cancer survivor', regardless of the cause of death (Khan et al, 2011). At the time, the NCCS endorsement of the term 'survivor' advocated for patient empowerment, high-quality care for the increasing number of people living past a diagnosis and ensuring that resources and support were tailored towards this growing population (Clark and Stovall, 1996).

Despite its widespread use, there is a lack of consistency within the extant literature and indeed in wider society as to what constitutes a 'cancer survivor' (Cheung and Delfabbro, 2016) and definitions are often formulated based on the researcher's area of interest (Twombly, 2004). Whilst new definitions have emerged over recent decades, as survival rates have increased, there is still a notable disparity with what the term 'cancer survivor' and 'cancer survivorship' mean to different people with some suggesting caution when using the term 'survivor' so as not to alienate those with a diagnosis whom do not identify with it (Cheung and Delfabbro,

2016). In fact, qualitative research in the UK has found that people with cancer do not endorse the term 'cancer survivor' (Khan et al, 2011) and this lack of enthusiasm for the terminology was echoed in an American study with women who have had breast cancer (Kaiser, 2008). Definitions have ranged from those who are first diagnosed with cancer to those living with a diagnosis for five years or more (Feurstein, 2007) whereas contrasting definitions have extended to include friends, family and caregivers (Bell and Ristovski-Slijepcevic, 2013).

At the same time, definitions can also differ by geography, where in Australia and Europe the term in a general sense refers to those who have completed primary treatment or who have lived 3-5 years from diagnosis (Surbone et al, 2013). Conversely, a concept analysis of the term revealed that a survivor is someone who is living with a history of malignancy, who has lived through a difficult experience and been impacted in positive and negative ways by it, and is in the follow up phase of their cancer treatment (Hebdon et al, 2015). Therefore, over the last decade, there has been significant debate over as to when an individual becomes known (or seen) as a 'survivor' (Cheung and Delfabbro, 2016).

Whilst the term 'cancer survivor' is frequently used and cited in the international literature, notably, the USA (Khan et al, 2011). In the UK, the National Cancer Survivorship Initiative (NCSI), a partnership between the Department of Health and cancer charities, adopted a broad definition as, 'those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease' (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010). The NCSI was a proponent of a cultural shift in cancer care that focused on recovery, health and wellbeing and support for self-management. Advancing on and influenced by the work of the NCSI, the UK charity, Macmillan Cancer Support has been an advocate of the terms 'living with, and beyond cancer' (Macmillan Cancer Support, 2014) and more recently 'living with cancer' (Macmillan Cancer Support, 2019) in that a diagnosis is something that anyone who is affected will live with for the rest of their life.

Indeed, the term 'survivor' may not carry positive connotations related to 'resilience' and people can perceive it to be a negative label that ties them to a traumatic life event (Surbone et al, 2013). Some research suggests that individuals would prefer to be known as 'someone who has had cancer' (Bellizzi and Blank, 2007) and again findings from the UK support this (Khan et al, 2011). At the same time, identifying as a 'survivor' or 'someone who has conquered

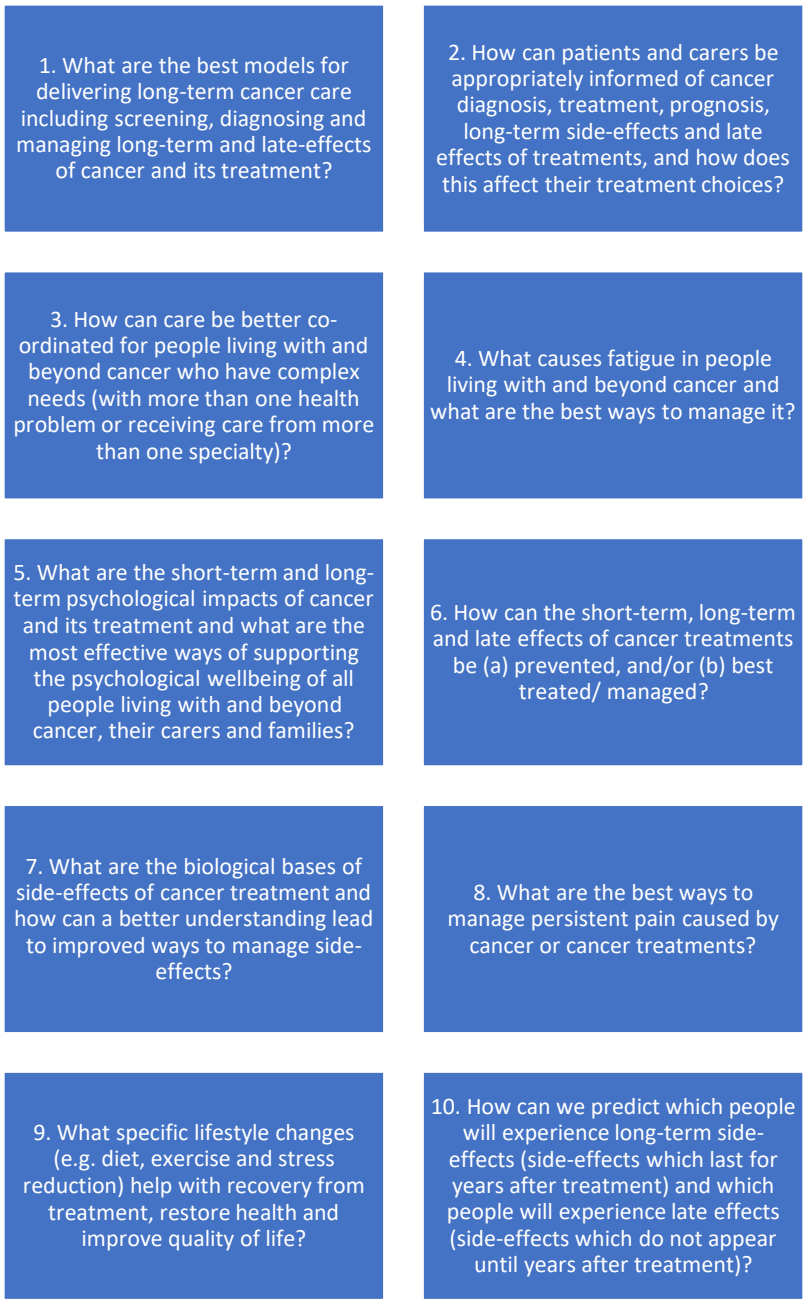
cancer' as opposed to a 'victim' or 'patient' can be empowering and impact some people positively (Bellizzi and Blank, 2007) in that they have overcome or 'battled' a life-threatening illness.

Whilst there is extensive research on the acute phase or primary treatment of cancer, it is well documented that people living past cancer and surviving long-term can experience different health and emotional needs than those recently diagnosed or currently undergoing acute treatment (Khan et al, 2012). It is therefore not surprising that research into the long-term consequences and late effects of cancer is flourishing as health professionals and researchers strive to find ways to improve both physical and mental wellbeing following diagnosis. The discipline of Psychosocial Oncology has been bolstered by the increasing popularity of organisations that promote research into the psychological, social and behavioural factors that influence survival, such as the International Psycho-Oncology Society (IPOS) and in the UK, the British Psycho-Oncology Society (BPOS). Indeed, scholars such as Foster et al, (2018) maintain that researchers in cancer survivorship have a duty to focus on the most pressing research questions that seek to improve the health and wellbeing of people affected by cancer. Again in the UK, the National Cancer Research Institute (NCRI) recently published the UK Top 10 Living with and Beyond Cancer Research Priorities (NCRI, 2018) at their annual conference in Glasgow (6th November 2018) that acknowledged the need for further research into a range of topics relating to psychosocial oncology in addition to short and long-term survivorship concerns (see Figure 1.3). This was the first time that clear research priorities were identified in this area and was the result of two national surveys with over three and a half thousand patients, carers and health and social care professionals (NCRI, 2018). It is important to highlight that engagement with self-management and supporting self-management are a common thread to all of the priorities below. Notably, priorities one, four, six, seven, and eight all explicitly refer to increasing understanding of managing frequently reported symptoms and side effects such as fatigue, pain, and other short-term/long-term/late effects of treatment.

In line with Feurstein's (2007) definition of a 'cancer survivor' this research collected data from individuals who had a past diagnosis of cancer and who had completed primary treatment. It has been widely acknowledged that there are people who continue with "treatment" or management and that it may be unclear when primary treatment ends, however, they will have completed the major aspects of treatment such as, surgery, chemotherapy, radiotherapy, or a

combination of treatment modalities and have a desire or need to "get on with their lives" (Feurstein, 2007). Whilst this definition was used to inform this thesis, from this point on, and for the purposes of this research the terminology **'people affected by cancer'** was utilised to refer to the study population and sample. This was considered to be an accessible and inclusive term when it came to accounting for the extensive differences in individual experience and the patient pathway that can impact an individual following a cancer diagnosis and subsequent treatment.

Figure 1.3 UK Top 10 Living with and Beyond Cancer Research Priorities

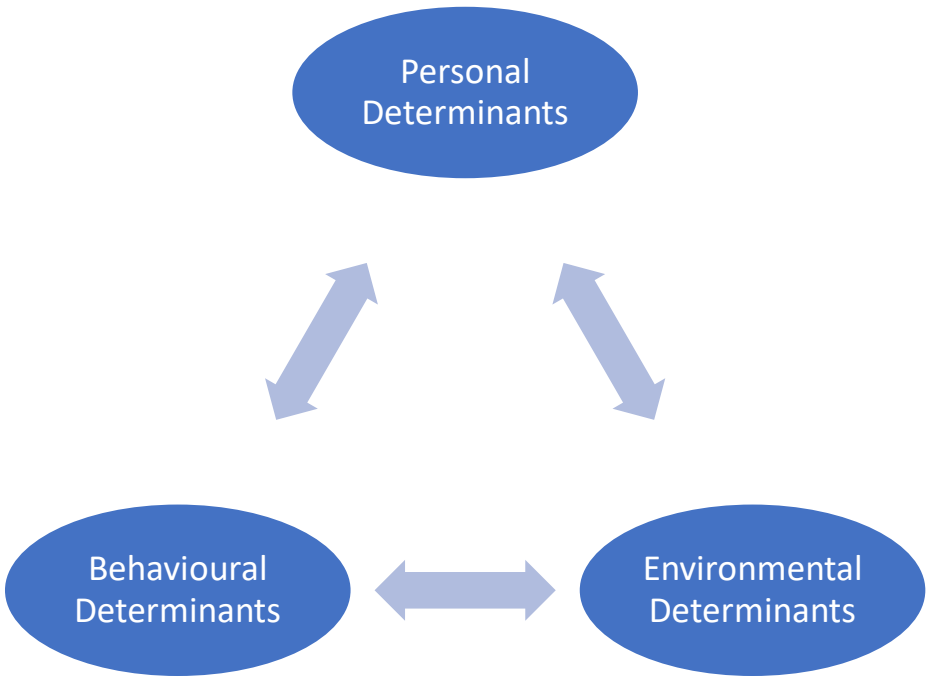


Adapted from NCRI (2018)

1.5 Self-Management

Historically, one of the first uses of the term 'self-management' within a healthcare context appeared in research on the rehabilitation of chronically ill children (Creer and Christian, 1976; Creer et al, 1976). For Creer and colleagues, self-management indicated that the patient was an 'active participant' in their treatment and this would eventually go on to inform the development of 'patient activation' which is discussed later in this chapter. Since then, self-management has been used in a variety of contexts perhaps none more so when referring to chronic disease patient education programmes (Lorig and Holman, 2003). Much of the early research on self-management through to the present day has been heavily influenced by the work of seminal psychologist Albert Bandura (1977; 1986). Specifically, Bandura's (1986) framework for Social Cognitive Theory (SCT) where he argued that human self-development, adaption and change are realised through the triadic reciprocation of (1) personal determinants, (2) behavioural determinants and (3) environmental determinants (see Figure 1.4). For Bandura, people are contributors to their life circumstances and not just products of them (Bandura, 2008).

Figure 1.4 Bandura's Social Cognitive Theory (1986)



SCT is a theory that can be utilised in behaviour change interventions (Bandura, 2004) as it provides a framework for understanding why individuals perform and maintain certain health-promoting behaviours (e.g. adhering to a healthy diet, engaging with physical activity) and it has been used to inform interventions with people affected by cancer (Stacey et al, 2015). The main constructs of SCT are: (1) knowledge of health benefits and risks; (2) perceived self-efficacy that the individual can control their own health behaviours; (3) the expected costs and benefits (outcome expectations); (4) health goals (proximal and distal intentions to engage in behaviour; (5) perceived facilitators and social support; and (6) barriers to change (Bandura, 2004). Whilst knowledge of health benefits and risks can lay the groundwork for behaviour change it is not simply enough to instigate change on its own (Bandura, 2004). Notably, it is self-efficacy that influences outcome expectations as well as barriers/facilitators to change and all of the constructs in the model will impact on health goals. Self-efficacy refers to the belief that an individual has to successfully execute behaviour needed to accomplish a goal or to produce an expected outcome (Bandura, 1986). Additionally, all constructs in SCT influence behaviour and motivation and will be dependent on the person's environment. Self-efficacy can be considered the central construct of SCT because it influences behaviour directly through the individual's belief in their ability to perform specific tasks in a range of situations, as well as indirectly, through influencing goals, outcome expectations, and barriers/facilitators (Bandura, 1998; 2004). It is therefore not surprising that self-efficacy is a key component of Foster and Fenlon's (2011) framework for recovery of health and wellbeing following cancer treatment (see Figure 1.5), as it has the potential to influence motivation, and as it increases it allows the individual to expect positive outcomes, overcome barriers, maintain commitment to goal setting that then subsequently leads to engaging with health behaviours and self-management (Bandura, 1998). Nonetheless, since Bandura first introduced self-efficacy (Bandura, 1977), it garnered criticism from scholars during the 1980s and 1990s who were critical of the idea that self-efficacy is free from the causal influence of expected outcomes (Corcoran, 1991; 1995; Kirsch, 1986; 1995; Maddux, 1999). More recently, Williams (2010) maintains that the lack of criticism into the twenty first century has led to a disproportionate focus on self-efficacy as a causal determinant of behaviour at the expense of expected outcomes. Thus, implying that non-engagement in adaptive behaviour is frequently a result of a lack of motivation based on perceived consequences as opposed to incapability independent of perceived consequences. Therefore, for Williams (2010), expected outcomes of behaviour should not be viewed as 'absolute' reasons for engaging (or not engaging) with a behaviour.

Globally, people are living longer and are increasingly self-managing long term and chronic conditions. Consequently, the burden of meeting the needs of this growing population frequently falls upon health services that are struggling to cope with the demands of acute care let alone the needs of those with long-term conditions (Barlow et al, 2002). For Barlow et al (2002), the more active involvement in healthcare that is demanded by individuals is in line with the realities of having a long-term or chronic condition where responsibility for day to day management is frequently shifting from healthcare professionals to the individual. Notably, this has developed in line with shifts away from paternalistic models of care where the patient is a passive recipient. Lorig and Holman (2003) contend that whether one is engaging in health-promoting behaviours (e.g. exercise, adhering to a healthy diet) or living with a chronic condition such as diabetes, they are responsible for day-to-day management. However, Glasgow (2012) and Roulstone and Morgan (2009) have been critical of the increased attention on self-management and self-care, particularly during times of economic austerity. They contend that self-management initiatives are frequently portrayed as being politically neutral, where instead, they take on distinctly neoliberal traits. Notably, aiming to devolve public health responsibility to the private sector, thereby creating a healthy and active individual whose goal is to return to an economically productive life.

There is no consistent or universal definition of self-management in the academic literature or indeed in wider society and it can mean different things to different people. In relation to chronic conditions, it has been defined by Barlow et al, (2002) as the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. For Lorig and Holman (2003) self-management reflects the extent that an individual chooses to engage or not engage with a healthy behaviour, actively regulate their disease, or manage their health. In their work with people who have rheumatic diseases, Alderson et al, (1999) refer to self-management as inter-disciplinary group education that is based on the principles of adult learning, individualised treatment, case management and self-efficacy enhancement. However, as Barlow et al, (2002) points out, this definition clearly disregards any individualised approaches to self-management. In their work on self-management of hypertension, Nagakawa-Kogan et al, (1988) consider self-management as a treatment that combines biological, psychological and social intervention techniques with a goal of maximal functioning of regulatory processes. In the past, self-management has been associated with self-care (Wilkinson and Whitehead, 2009) and the two terms have at times been used interchangeably. Nevertheless, there is a marked difference,

specifically, the lack of or minimal involvement of health professionals in self-care (Cockle-Hearne and Faithfull, 2010) and in its simplest form, self-care can be considered behaviour performed by individuals on their own to promote health and wellbeing (Orem, 2001). For Clark et al, (1991) self-care can be considered a preventative strategy that encompasses tasks performed by healthy people on their own at home. Conversely, self-management is an interactive process whereby individual responses and behaviour aimed at managing physical and psychosocial consequences of symptoms and treatment are supported by a clinician or other health professional (Cockle-Hearne and Faithfull, 2010). Furthermore, Clark et al, (1991) maintain that individuals with chronic conditions must manage daily living in line with their financial and social conditions. They go on to suggest that for self-management to be successful the individual requires sufficient knowledge of the condition and its treatment

In their qualitative work with people who have chronic conditions, Corbin and Strauss (1988) categorise self-management into three sets of tasks (1) medical management (2) role management and (3) emotional management. Firstly, medical management refers to how an individual medically manages their condition such as taking medication or attending medical appointments. For example, some women take tamoxifen (a hormonal therapy drug) for up to five years following initial treatments for breast cancer to reduce the risk of breast cancer recurrence (Cuzick et al, 2015). The next set of tasks involves maintaining, changing, and creating new meaningful behaviours or life roles (Lorig and Holman, 2003). For example, someone with chronic back pain may need to adjust or change the way they participate in physical activity. For someone recovering from cancer who is suffering from fatigue it might mean avoiding driving when they feel tired or spreading housework tasks over the week and asking for help from friends and family if available. The final task relates to dealing with the emotional consequences of having a chronic condition. Emotions such as anger, fear, frustration, depression and anxiety are frequently experienced by someone with a chronic condition (Lorig and Holman, 2003) including people affected by cancer (Mitchell et al, 2013) where fear of cancer recurrence can be a salient issue among long-term survivors (Koch et al, 2013) Therefore, learning to manage emotions becomes an inherent task with the wider self-management of their condition.

1.6 Self-Management and Cancer Survivorship

For many decades, cancer had largely been perceived as an acute illness, however, increasing survival rates have seen it firmly situated within the framework for chronic and long-term conditions. Advances in clinical care have meant that many people diagnosed and treated will go on to live for several years with some living well and free from active disease (Maher and Fenlon, 2010). Nonetheless, people experience significant side effects from the disease and its treatment, and as cancer care has shifted to a personalised and long-term approach, there has been a significant drive towards promoting and supporting self-management with people affected by cancer (Boger et al, 2015; Cimprich et al, 2005; Cockle-Hearne and Faithfull, 2010; Foster and Fenlon, 2011; Gao and Yuan, 2011; Howell et al, 2017; Macmillan Cancer Support, 2015; McCorkle et al, 2011). Furthermore, self-management is now a common theme in the cancer survivorship literature with several existing literature reviews published in recent years (Boland et al, 2018; Cockle-Hearne and Faithfull, 2010; Coffey et al, 2016; Gao et al, 2011; Hammer et al, 2015; Howell et al, 2017; Kim et al, 2017; McCorkle et al, 2011; Papadakos et al, 2018; Paterson et al, 2015).

Self-management has frequently been associated with the concept of self-care (Wilkinson and Whitehead, 2009), however, there is a marked difference, notably, the lack of or minimal involvement of health professionals in self-care (Cockle-Hearne and Faithfull, 2010). In its simplest form, self-care can be considered behaviour performed by individuals on their own to promote health (Orem, 2001). It is regarded as a broad term that can encompass all actions or behaviours that people take to care for themselves. Comparatively, self-management can be considered an interactive process whereby individual responses and behaviour aimed at managing physical and psychosocial consequences of symptoms and treatment are supported by a clinician or other health professional (Cockle-Hearne and Faithfull, 2010). At their core, engagement with self-care and self-management advocate health and wellbeing, therefore, there is a natural synergy when considering these two concepts. However, for the purposes of this research the focus was explicitly on ‘self-management’ in the context of cancer care and how individuals manage the long-term effects of a cancer diagnosis and treatment.

In cancer survivorship, self-management has been defined as “awareness and active participation by the individual in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and wellbeing” (Department of

Health, Macmillan Cancer Support and NHS Improvement, 2010). This involves managing the physical, psychological, social and practical consequences of cancer and its treatment, as well as understanding how and when to seek support, recognising signs of disease progression and making lifestyle changes to promote health and wellbeing (Foster et al, 2015). People can be supported to self-manage in a range of ways including by healthcare professionals, peers, employers, friends and family, as well as, with digital and online resources (Foster and Fenlon, 2011). Indeed, recent research by Brett et al, (2018) found that an e-health app designed to support women affected by breast cancer facilitated the exchange of suggestions for self-management strategies via peer support. Therefore, self-management is very much dependent on a collaborative relationship albeit with the onus firmly on the individual to initiate contact with healthcare professionals and other sources of support (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010). At the same time, a formidable barrier is that self-management support is not always readily available and confidence to access and engage with it can be low (Foster and Fenlon, 2011). Therefore, people affected by cancer need the appropriate resources to facilitate self-management and ease the burden on health services (Cavers et al, 2019). Particularly, in rural and remote areas, specialist cancer services are not always locally provided meaning people often have to travel long distances to access support (Buzza et al, 2011; Smith, 2012; Virani et al, 2011). Additionally, disparities in mental health between people affected by cancer from rural and urban areas have been reported (Burris and Andrykowski, 2010) which could present a significant barrier to engagement with self-management practices and self-management support. Despite this evidence, there is still a lack of research that specifically examines and compares the role of rural-urban residency on self-management following cancer treatment.

Lorig and Holman (2003) maintain that self-management typically incorporates five core skills of: (1) problem solving, (2) decision making, (3) resource utilisation, (4) communication with health professionals and (5) action planning or goal setting. It is dependent on the application of these five skills to one's individual situation. In cancer care, self-management interventions facilitated by health professionals are frequently becoming an integral part of treatment as they increase the patient's knowledge of issues arising post-treatment such as anxiety or emotional distress (Boland et al, 2018). That said, there is a lack of consistency when it comes to signposting and neither health professionals nor patients are always aware of the support that is available. Moreover, self-management support may not always be accessible to those in hard to reach or remote areas. However, where self-management initiatives are accessible and

utilised, they have the potential to empower individuals, increase their confidence to manage problems and enhance quality of life (Barlow et al, 2005; Lorig et al, 2001). Interventions to support self-management can take a variety of forms and are delivered in a range of ways, such as online, individually or in groups (Fenlon et al, 2013). They include programmes specifically targeted at increasing an individual's ability to self-manage or training in specific techniques or behaviours, e.g. coaching, relaxation, cognitive behavioural therapy (CBT), mindfulness and self-delivered acupuncture (Fenlon et al, 2013). Notably, some of the self-management interventions from the extant literature include the Expert Patient Programme (Rogers et al, 2008), Taking CHARGE (Cimprich et al, 2005), RESTORE (Grimmet et al, 2013), PRO-SELF (Dodd et al, 2010), and The Living with Cancer Education Programme (Todd et al, 2002).

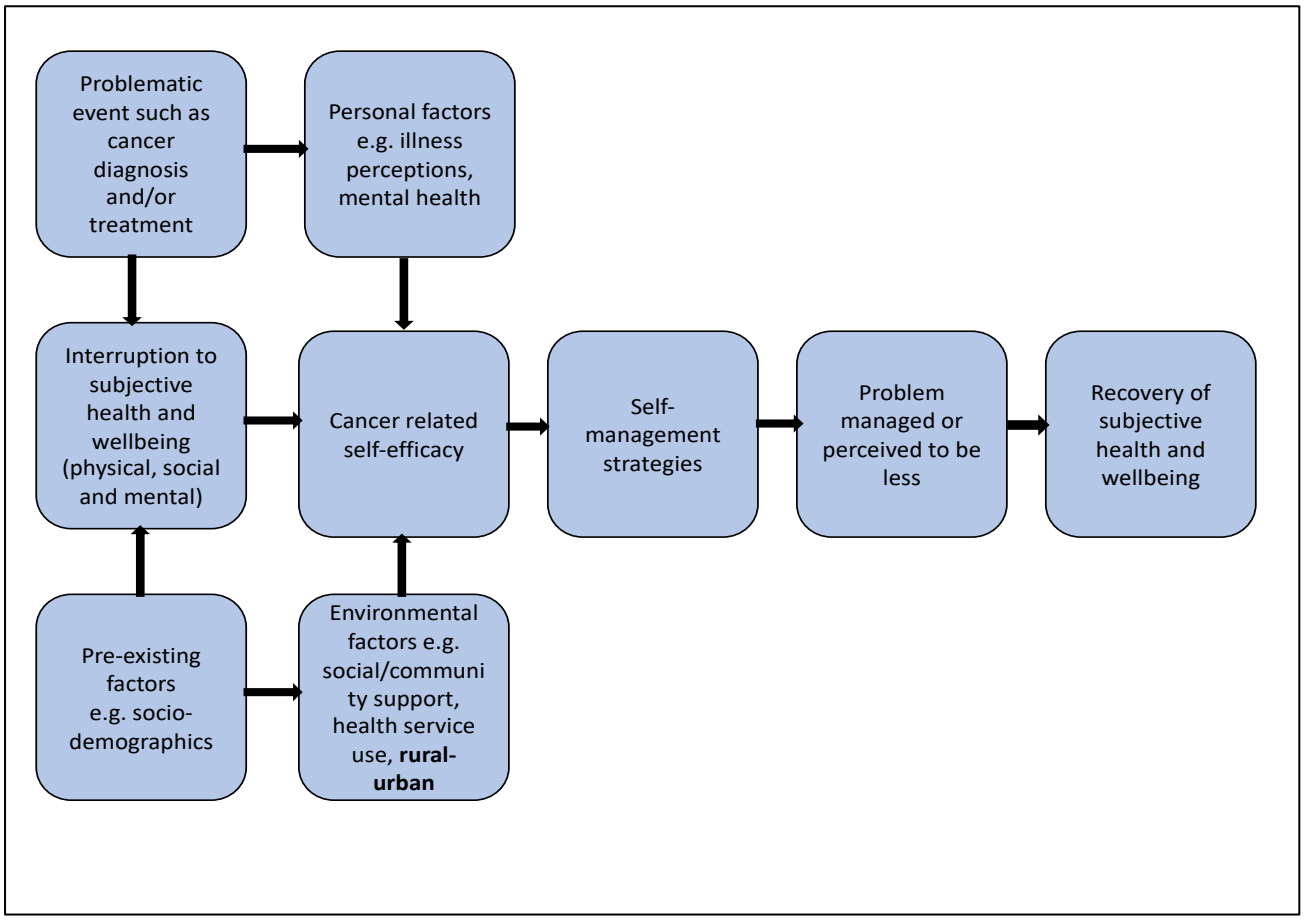
Despite self-management being problematic to define, existing research with people affected by a cancer diagnosis (Shneerson et al, 2015a; 2015b) attempted to categorise self-management strategies and practices into the following six broad categories: (1) diet and nutrition (2) physical activity (3) psychological therapies (4) support groups (5) spirituality and religious practices and (6) complementary and alternative medicine. Through engaging with self-management practices and behaviours such as these, people who have been diagnosed with cancer can improve their health and wellbeing whilst easing pressure on healthcare resources and promoting patient choice (Coffey et al, 2016; Davies and Batehup, 2010). That said, these practices will not be for everyone and whilst engaging in complementary and alternative medicine might support self-management in one person affected by cancer, it might not work for someone else who prefers going to a local support group. The range and frequency of engagement with the above will very much depend on the individual and their own personal circumstances. This doctoral research used Walker et al's, (1995) Health Promoting Lifestyle Profile II (HPLP-II) scale in order to best accommodate engagement with the above categories that were identified by Shneerson et al (2015a; 2015b). Health behaviours are an integral component of self-management and the HPLP-II uses a four point scale that assesses the frequency an individual engages with a range of health-promoting behaviours on: (1) physical activity (2) health responsibility (3) spiritual growth (4) nutrition (5) interpersonal relations and (6) stress management. More importantly, this allowed for comparison of engagement with health-promoting behaviours, such as physical activity between rural and urban populations who were affected by cancer (see Chapter 5: 5.10.3 HPLP-II). Traditionally, health promotion has long been associated with cancer prevention, however, this is something that conceptually

together with self-management has shifted to the forefront of survivorship care, aiming to improve health and wellbeing through adherence to a healthy lifestyle.

1.7 Cancer-Related Self-Efficacy

Prominent British psychosocial oncology academics, Claire Foster and Deborah Fenlon (2011), developed a conceptual framework for recovery of health and well-being in cancer survivorship which has self-management and support for self-management as key components (see Figure 1.5). Another element of this framework is cancer-related self-efficacy which can be defined as belief that an individual can successfully execute behaviour required to produce an expected outcome (Bandura, 1986) in relation to the consequences of cancer and its treatment (Foster et al, 2015). It should be noted that increasing self-efficacy is increasingly becoming a goal of survivorship and self-management programmes (Halpern and Argenbright, 2017). Furthermore, Foster et al, (2013) developed an eleven-item scale to measure self-efficacy to manage problems following cancer treatment that has now been utilised as an outcome measure in a range of survivorship studies (Foster et al, 2015; Foster et al, 2016; Grimmet et al, 2017; Watson et al, 2016) as well as, one of the outcome variables in the quantitative phase of this thesis. Their scale is based on Lorig et al's (2001) Chronic Disease Self-Efficacy Scale where respondents rate their confidence (1 'not at all confident' to 10 'totally confident') to perform six self-management behaviours that are inherent to living with and managing a long-term condition. Expanding on this, Foster et al, (2013; 2015) added five cancer-specific self-management behaviours to the scale to create the Cancer Survivors Self-Efficacy Scale (CSSES). These five additional behaviours were in relation to: (1) accessing information about cancer (2) accessing people to help support with problems caused by cancer (3) dealing with problems caused by cancer by yourself (4) contacting the doctor about problems caused by cancer and finally, (5) getting support from health and social care professionals in relation to problems caused by cancer. Participants are given a mean value for each individual behaviour and for the CSSES as whole (range 1-10).

Figure 1.5 Framework for Recovery of Health and Wellbeing in Cancer Survivorship



Adapted from Foster and Fenlon (2011); Foster et al (2015)

According to Bandura (1977) higher self-efficacy has been associated with a greater effort and persistence to overcome challenges as well as enhanced wellbeing (Lev et al, 2001). In research with people affected by cancer, higher self-efficacy is associated with increased self-care behaviours and decreased physical and emotional symptoms (Lev, 1997). Importantly, Foster et al, (2015) maintain that self-efficacy is not a general trait that is applicable to all circumstances and is susceptible to change according to the task to be self-managed. Therefore, an individual cannot be described as having high or low self-efficacy in all situations. Indeed, individual belief about their confidence to perform certain tasks will vary according to the context and nature of the task (Foster et al, 2015). For example, an individual might have high self-efficacy when it comes to managing fatigue but less so when it comes to managing emotional distress.

In their study with adults who had completed primary cancer treatment (N=182) in the last twelve months, Foster et al, (2015) used the CSSES and identified that participants were least

confident when it came to managing fatigue (5.83±2.56), emotional distress (5.97±2.55) and other health problems (6.08±2.47). Participants were most confident when it came to accessing information with regards to cancer (8.22±2.00) and contacting the doctor about cancer (7.97±2.45). Mean scores ranged from 5.83-8.22 indicating wide variation in self-efficacy depending on the task to be managed. Furthermore, those more likely to report lower cancer-related self-efficacy were women, those with high levels of pain and/or depression, lower wellbeing scores, lower socio-economic status, low levels of social support, or a more negative perception of cancer.

Watson et al's (2016) work with men affected by prostate cancer (N=316) found that self-efficacy across all self-management behaviours on the CSSES was generally high (median score of at least eight across all eleven items) and respondents were in general, confident to manage fatigue, physical discomfort, emotional distress, and other symptoms or health problems. With regards to the cancer-specific items, participants were also mostly confident that they could access information and support, deal with problems caused by cancer by themselves, and contact the doctor regarding cancer. Participants with moderate to large symptom problems reported lower scores on all the self-efficacy questions, in some cases this was significantly lower. However, it should be noted that the reduction was less than one point on the ten point scale.

A further study by Grimmet et al, (2017) used the CSSES with colorectal cancer patients in the two years following diagnosis and found that greater deprivation, domestic status, more co-morbidities, worse fatigue and pain, lower positivity and greater negativity were associated with lower cancer-related self-efficacy. At two years, post-diagnosis, confidence was lowest to manage other symptoms or health problems which suggests that co-morbid conditions are sometimes more problematic for people to manage as opposed to the consequences of a cancer diagnosis and treatment. That said, cancer can very often exacerbate other long-term conditions or health problems as maintained by Edgington and Morgan (2011). However, a recent systematic review by Cavers et al, (2019) highlighted that there is limited research that focuses explicitly on the experience of living with cancer alongside other comorbid conditions.

Whilst Foster and Fenlon (2011) account for the role of environmental factors in their framework (see Figure 1.5) and posit that these can influence cancer-related self-efficacy, self-management strategies and subsequent health and wellbeing, no research until now, has

examined specifically, the environmental factor of geography (rural-urban residency) in relation to this following cancer treatment. Therefore, this study addressed this gap by identifying and comparing cancer related self-efficacy in both rural and urban populations using the Cancer Survivors Self-Efficacy Scale (CSSES) (see Chapter 5: 5.10.5: CSSES).

1.8 Patient Activation

Whilst cancer-related self-efficacy is concerned with confidence to perform specific health tasks and behaviours, some of which directly relate to self-managing the consequences of cancer, a further way self-management can be quantified is by using the Patient Activation Measure (PAM). Whilst the two concepts of 'self-efficacy' and 'patient activation' have a natural synergy, several health researchers (Do et al, 2015; Krouse et al, 2016; Kvale et al, 2016; Young et al, 2017) have recognised these as distinct outcomes in their own right and used them simultaneously to collect and compare data, as was also the case in this thesis. The extant literature points to the measurement of patient activation and self-efficacy to evaluate the effectiveness of self-management interventions (Krouse et al, 2016; Kvale et al, 2016) and further research has found that activation is associated with both, self-efficacy, and engagement with health-behaviours (Do et al, 2015; Young et al, 2017).

People have to make a range of choices in their daily lives that have considerable implications for their health and their care needs (Hibbard et al, 2005). Specifically, those with chronic and long-term conditions, such as cancer, frequently need to follow complex treatment regimens, monitor their condition(s), make lifestyle adjustments, and make decisions about when they need to seek help from professionals and conversely, when they feel they can manage a problem on their own (Hibbard et al, 2005). The Chronic Care Model (CCM) advocates for healthcare system redesign, that enables proactive healthcare professionals to interact with "informed and activated patients" as well as, patient centred care that situates the patient and their families as key components of their own care team (Von Korff, 1997; Wagner, 1998). Therefore, to be an effective "self-manager" of one's health and healthcare, particularly when suffering from at least one chronic condition requires an individual with a significant level of 'patient activation' who is a collaborative partner when it comes to managing their health (Hibbard et al, 2005; 2007).

Patient engagement and patient activation are frequently used interchangeably (Hibbard and Greene, 2013), patient engagement refers to the broad involvement of individuals in all aspects of their healthcare and is based on the principle of shared responsibility (Danis and Solomon, 2013). Patient activation can be considered a key component of patient engagement and has been defined as the knowledge, skills and confidence a person has to manage their health and health care (Hibbard et al, 2004) and has recently received increasing attention across the NHS in relation to person-centered long-term condition management (NHS England, 2016; 2018). It is being used as an indicator of quality and effectiveness as well as a tool to tailor and stratify the delivery of care or to identify individuals at risk of poor-self-management (Roberts et al, 2016). At the same time, due to a lack of published UK data, we still know little about what influences activation with different long-term conditions in the UK (Blakemore et al, 2016; Roberts et al, 2016) and even less with regards to people affected by cancer who reside in the UK. Indeed, the limited peer-reviewed work from the UK has tended to focus on long-term conditions in general (Blakemore et al, 2016; Roberts et al, 2016) and has highlighted that factors such as age, employment status, health literacy, quality of life and social support can all influence patient activation (Blakemore et al, 2016).

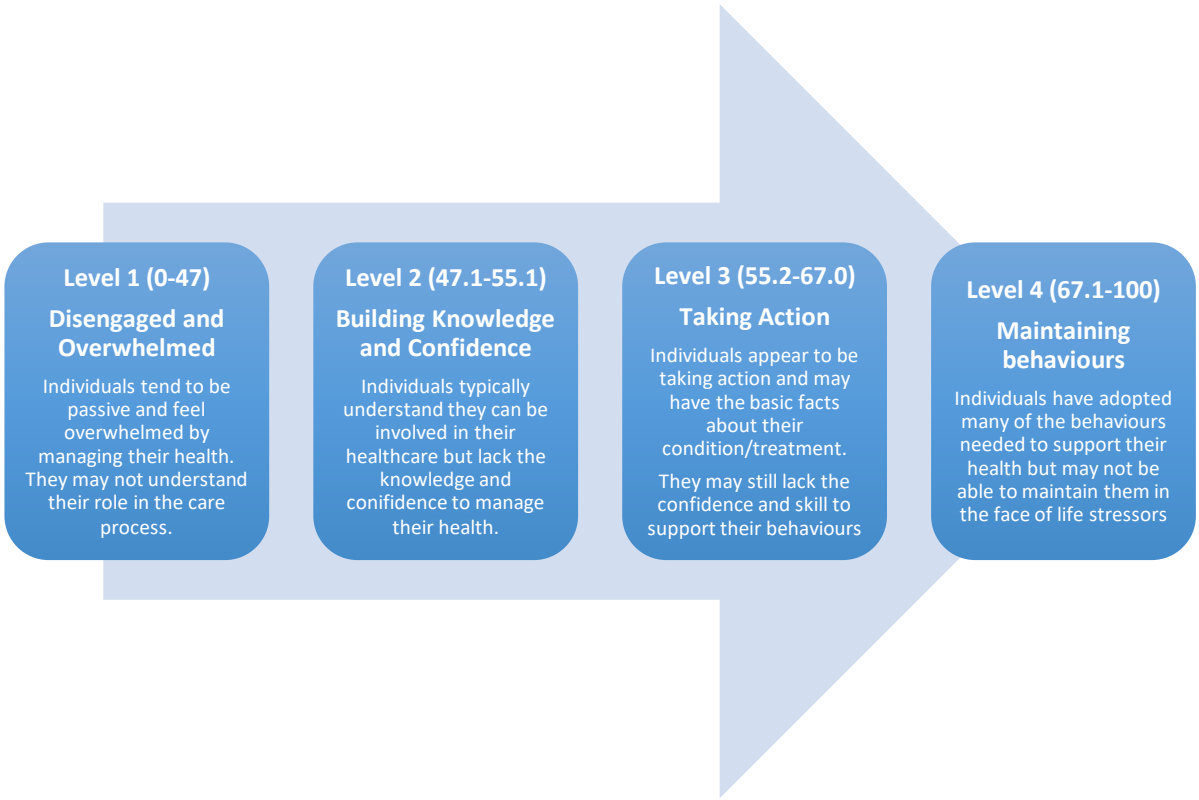
Patient activation is frequently measured using the Patient Activation Measure 13-item scale (PAM-13) developed by Hibbard et al, (2004; 2005) and is scored on a 0-100 scale where a higher score indicates that the respondent is more "activated". The PAM-13 contains thirteen statements about beliefs and confidence in the management of health-related tasks and self-assessed knowledge (Hibbard and Gilburt, 2014) and respondents are asked to rate the degree to which they agree or disagree with each statement. Additionally, the overall activation score categorises the individual into one of four levels of activation (see Figure 1.6) each of which offers insight into a range of health-related characteristics and behaviours. The levels represent progression from someone who is a passive care recipient (Level One) right through to someone who is highly proactive about self-managing their health (Level Four) (Hibbard et al, 2004; 2005). Whilst it has been applied in a range of healthcare contexts, it should be noted that activation is not unique to any specific condition and the PAM is not focused on one specific behaviour (Greene et al, 2015). Consequently, activation is broader than earlier concepts that precede it such as locus of control, self-efficacy and readiness to change, which tend to focus on changing one behaviour (Greene et al, 2015). Activation aligns itself with a wider range of outcomes when compared to these previous concepts (Skolasky et al, 2009; 2011).

Improving patient activation is increasingly seen as a fundamental component of novel strategies to reform healthcare and improve health outcomes (Hibbard and Gilburt, 2014). There is increasing evidence that patients who are more activated have better health outcomes and care experiences (Hibbard and Greene, 2013) and the level of activation determines the individual's understanding of their role in managing their health as well as their willingness and ability to take independent actions and decisions to self-manage (Greene and Hibbard, 2012; Hibbard and Cunningham, 2008). Individuals with long-term conditions, who are highly activated, are more likely to engage with healthy behaviours and to manage their health more effectively (NHS England, 2018). Indeed, those with higher levels of activation have reduced probability of adverse markers such as emergency department use, obesity and smoking (Greene and Hibbard, 2012; Hibbard and Greene, 2013). Much like self-management, activation can be self-directed or facilitated (but not led) by professionals and/or peers (Roberts et al, 2016) with the onus situated firmly on the individual. On the other hand, people with low levels of activation are less likely to play an active role in staying healthy and are less capable of seeing help when they need it, at following advice from health professionals and at managing their health when they are no longer being treated (NHS England, 2018). Globally, healthcare systems are advocating that primary care providers practice patient-centred care by utilising strategies that engage with and enhance patient activation (Gessert et al, 2015). Moreover, the increasing focus on patient-centred care presents considerable challenges to policy makers, the health and social care workforce and patient advocates to better understand the factors that can influence patient activation and self-management.

In relation to cancer survivorship, there is limited research on patient activation with this population group (Hibbard et al, 2017) and specifically, with rural-urban populations. Research by Hung et al, (2013) suggests that the PAM-13 is a valid tool for use with rural populations. Much of the cancer research that does exist has a tendency to focus on preventive cancer screening (Greene and Hibbard, 2012), attitudes towards cancer (Hay et al, 2016), satisfaction with care (Wind et al, 2016), adolescent and young adult cancer patients or are most frequently conducted with North American populations (Dingley and Roux, 2014; Jiang and Hong, 2018; Kvale et al, 2016; O'Malley et al, 2016). As previously mentioned, the increasing number of people surviving cancer means they are having to self-manage the consequences of diagnosis and treatment on a long-term basis, therefore, there is a pressing need to enhance the understanding of patient activation with this specific group. That said, there are a small number of studies that are beginning to look at patient activation with people affected by cancer

following treatment (Bernat et al, 2017; Hibbard et al, 2017; Mazanec et al, 2016; O'Malley et al, 2017; van Maarschalkerweerd et al, 2017).

Figure 1.6 Four Levels of Patient Activation (Hibbard and Gilburt, 2014; Roberts et al 2016)



According to Hibbard et al, (2017) activation level is associated with cancer patient experiences from diagnosis to survivorship and people affected by cancer who are less activated are more susceptible to poorer health outcomes. In their study, when controlling for demographics and health status, the findings highlighted that higher activated patients were 4.7 times more likely to have started to exercise and 3.3 times more likely to have started to eat a healthier diet compared to less activated patients. Furthermore, the more activated patients were 3.2 times more likely to feel they had sufficient information regarding treatment risks, 4.5 times more likely to effectively manage side effects, and forty five per cent more likely to take medications as directed when compared to less activated patients. Finally, the less activated patients were less likely to adhere to doctor's recommendations compared to more activated patients.

Further research by O'Malley et al, (2017) assessed rates of patient activation in people affected by breast (N=213) and prostate (N=112) cancer, as well as, exploring the characteristics of participants that were associated with patient activation. The overwhelming majority of participants were the highest level four (45%) or moderately highest level three (41%) of activation. This was similar to findings by Mazanec et al, (2016) with people affected by colorectal cancer. Furthermore, only five per cent of the participants in O'Malley et al's, (2017) research were level one and nine per cent categorised as level two. Additionally, the results highlighted that participants affected by breast cancer were more highly activated than those who had prostate cancer. Interestingly, demographics were not associated with activation in those who had breast cancer. Conversely, race, marital status and employment status were associated with activation in participants who had prostate cancer and activation was lowest amongst participants with prostate cancer who were not married, unemployed and had lower incomes. In both groups, access to primary and secondary care providers were associated with activation. It should be noted that no data were collected with regards to residency or rural-urban geography.

Activation scores were calculated for 417 Dutch people affected by cancer (van Maarschalkerweerd et al, 2017) and similarly to Jiang and Hong (2018) they found that activation was associated with age and level of education. In this research (van Maarschalkerweerd et al, 2017), on the relationship between people affected by cancer's level of activation and participation in paid work, most respondents were categorised as level three (33.6%), almost a quarter were either level two (24.0%) or level four (24.0%) and the least were categorised as level one (18.5%). Interestingly, activation was not associated with engagement in paid work, although employed participants with a low level of activation experienced more problems working accurately, finishing their work and concentrating compared to those with higher activation. Finally, those who were employed with low activation tended to report more work-related stress compared to those in employment with high activation.

According to Bernat et al, (2017) the frequent interaction that people affected by cancer have with the healthcare system and health professionals during their treatment means that they might be more activated than those with no history of cancer. In fact, their data from the American 2013 Health Information National Trends Survey (N=3185) indicates that people affected by cancer were approximately seventy per cent more likely to be highly activated

compared to those with no history of cancer (Bernat et al, 2017). Notably, in this study, activation did not seem to decrease over time and remained relatively stable throughout survivorship which is in line with research by Mazanec et al, (2016) on activation levels with patients and caregivers who have been affected by colorectal cancer.

Therefore, the PAM-13 was also utilised as one of the outcome variables in the quantitative phase of this study allowing for comparison between rural and urban participants (see Chapter 5: 5.10.4: PAM-13). For the most part, rural communities tend to be less researched than their urban counterparts (Buzza et al, 2011; Virani et al, 2011) and rural individuals have been reported to be hospitalised more often than those from urban areas (Hartley, 2004) and face more barriers to access, including increased travel and limited speciality care (Buzza et al, 2011; Virani et al, 2011). It is common that rural areas have a substantial elderly population with increased prevalence of long-term conditions so it would be right to hypothesise that a construct such as patient activation, that allows us to quantitatively measure knowledge, skills and confidence to self-manage, will be different between rural and urban populations who have a history of cancer.

1.9 Rationale for the Study

According to Rojon and Saunders (2012), explaining the purpose of a research project and providing a compelling rationale is an integral part of any study, thus allowing the work to be situated within the context of both existing evidence (see Chapter 2) and its implications for practice (see Chapter 8). With that in mind, this study builds on and contributes to work in the field of self-management and cancer survivorship by explicitly offering a better understanding of the experiences of people affected by cancer in rural and urban settings. Despite the increased attention on self-management from policy makers (NHS England, 2017), academics (Foster and Fenlon, 2011; McCorkle et al, 2011), charities (Macmillan Cancer Support, 2017), and health and social care professionals (Burd et al, 2016), there was a lack of research examining whether rural-urban geography had a significant bearing on an individual's ability to self-manage their health and health care following cancer treatment. Whilst research into self-management and cancer has increased extensively over the last decade, initial scoping searches of the peer-reviewed academic literature reinforced that the role of rural-urban residency in relation to this was an under researched area that warranted further investigation via the collection of primary data. Therefore, this research addressed that gap in the evidence

through recruiting people affected by cancer who resided in both rural and urban parts of the East Midlands of England with a primary focus on the counties of Lincolnshire and Leicestershire (see Chapter 4: 4.7.3 Study Setting).

It has been well documented that people affected by cancer in rural settings experience a number of additional challenges in addition to their urban counterparts such as traveling for treatment, access to specialised support and they are more likely to have unmet psychosocial needs as well as poorer treatment outcomes (Butow et al, 2012; Harrison et al, 2009). Specifically, mental health disparities have been highlighted in the literature with those in rural areas reporting poorer mental health compared to urban (Burris and Andrykowski, 2010). Furthermore, studies that have compared quality of life between rural and urban groups report inconsistent or mixed findings (DeSipio et al, 2012) are revealing poorer outcomes for those in rural areas (DeSipio et al, 2012; Lyons and Shelton, 2004; Weaver et al, 2012; 2013) or finding no differences between groups (Burris and Andrykowski, 2010). Interestingly, a study in Ireland reported that people who had head and neck cancer in rural areas had significantly greater physical and emotional quality of life than those in urban areas although social and functional quality of life did not significantly differ by geography (Thomas et al, 2014). Whilst these aforementioned studies focused on outcomes in relation to mental health and quality of life which are undoubtedly integral to influencing self-management and cancer recovery, they have not explicitly addressed and measured self-management in its own right using quantitative outcome measures such as the PAM-13 or CSSES.

Understanding the cancer survivorship experiences of people in both rural and urban parts of the UK is of vital importance given almost a fifth (11.13 million) of the UK's total population (66.04 million) reside in what can be classed as rural (The World Bank, 2017). It should be noted that the cancer survivorship studies that have explicitly focused on geography tend to be set outside of the UK with much of the existing research conducted in the USA, Canada and Australia (Burris and Andrykowski, 2010; Butow et al, 2012; Weaver et al, 2012; Weaver et al, 2013; Yao et al, 2017). Specifically, these studies have tended to focus on mental health (Burris and Andrykowski, 2010), health status (Weaver et al, 2012) as opposed to a direct focus on self-management. Again, other studies have focused on specific cancer types within a rural setting such as breast (Meneses et al, 2009) or colorectal cancer (Baldwin et al, 2008). Some of the more recent quantitative research on self-management in cancer in the West Midlands region of the UK has looked at variations in demographic factors (Shneerson et al, 2015a),

associations between self-management and quality of life (Shneerson et el, 2015b) and qualitative research on self-management practices as mechanisms for re-establishing normality post-treatment (Henshall et al, 2017). Whilst these studies serve to enhance the field, notably within a UK context, they do not tell us anything about the role of rural-urban residency in relation to self-management following cancer treatment. This PhD thesis was designed to further enhance our understanding specifically with people affected by cancer in a UK context where research is limited when it comes to comparing between rural and urban geographies. Furthermore, the research was designed to include heterogeneous cancers that aimed to generate welcome insight into the cancer experience as whole, regardless of cancer type, whilst also accounting for and reporting on the substantial differences in the cancer journey that can be dependent on tumour site and treatment modality.

For a considerable period of time, much of the health related cancer research tended to focus on the acute and active treatment phases of the cancer journey and there has been an increasing call for further research into the survivorship experiences of people affected by cancer following treatment (McNulty and Nail, 2015). Again, this study has been designed to enhance our understanding of the longer-term post-treatment experiences of managing cancer by recruiting those who were up to five years following the completion of primary treatment and the quantitative and qualitative data generated through this research offered valuable insight into these experiences in relation to the role of rural-urban residency.

Some of the most recent research in Australia by Gunn et al, (2019) reported that people affected by cancer in rural areas when compared to urban, were more likely to have trust in their communities, were less likely to report higher distress, and equally likely to report a mental health condition. Interestingly, in unadjusted analyses rural were more likely than urban to be obese and physically inactive, however, when adjusting for socioeconomic disadvantage these differences disappeared. Again, this study was designed to ascertain differences in health-promoting behaviours such as adhering to a healthy diet and engaging with physical activity within a UK context.

Research by Sowden et al, (2014) suggests that cancer could have a greater impact on employment amongst rural populations where they retired earlier compared to their urban counterparts and were less likely to go on paid disability whilst undergoing treatment. A systematic review conducted by Butow et al, (2012) on people affected by cancer in rural areas

highlighted that much is still unknown about the needs of people with cancer in rural and remote areas. This was evident through the somewhat homogenous articles that they retrieved where out of thirty-seven studies included in their review, twenty-five were quantitative (eleven of which included a control group of urban participants) and twelve used qualitative methods. With regards to cancer type, the majority of studies that were included had only people affected by breast cancer (N=15), mainly breast cancer (N=4), and breast and prostate cancer (N=3). Again, of considerable interest, the majority of studies (N=24) tended to focus on the active treatment phase. The findings point to rural patients having higher needs in the majority of controlled studies and they contend that this could be influenced by limited access to resources, a more self-sufficient lifestyle, such as being more stoical and less likely to seek support. Furthermore, the need to travel for treatment caused practical, emotional and financial problems and burdened patients with additional worry concerning family and work commitments. Despite these salient findings, Butow et al, (2012) emphasise the need for further research via population-based studies that include people with heterogeneous cancers from both rural and urban settings.

Again, in Butow et al's, (2012) systematic review, they note that few studies are explicit with regards to their definition of rurality. This can make comparison across studies even more problematic where a range of designs and measures have been adopted. Additionally, they contend that rurality in large and sparsely populated countries such as Australia can mean very different things to rurality in a smaller and more densely populated country such as the UK. That said, rurality can differ greatly in terms of what the public perceive as 'rural' and even across England there are significant variations in geography across the country (Department for Environment Food and Rural Affairs, 2017) where some areas are considered 'rural' but may lie in very close proximity to more densely populated urban cities and towns. It should be noted that this study offers considerable insight into the survivorship experiences of people in both rural and urban parts of England with a primary focus on the counties of Lincolnshire, Leicestershire and surrounding areas that are situated within the East Midlands.

In addition, the study makes a notable contribution to the cancer survivorship and self-management field through its methodological approach. The explanatory sequential mixed methods design (see Chapter 3: 3.7 Mixed Methods Research) that utilised both quantitative and qualitative methods of data collection meant that valuable insights could be drawn into the role of rural-urban residency in cancer survivorship, that could not have been generated had

quantitative or qualitative methods been used in isolation. Furthermore, the mixed methods design was novel and significant in that it utilised existing quantitative outcome measures such as the HPLP-II, PAM-13 and CSSES with a new study population, as well as, the use of open ended questions to collect qualitative data to further explore the role of rural-urban residency in relation to self-management.

Whilst it is increasingly recognised that psychosocial care is a key component of high-quality and comprehensive cancer care, provision can differ substantially based on geography (Ashley and Lawrie, 2016). Psychosocial care is generally more established and implemented in higher-income countries compared to less developed countries and is more likely to be provided in cancer centres and University Hospitals, which are frequently located in urban settings than in smaller facilities based in the community (Mehnert and Koch, 2005; Travado et al, 2017).

In terms of symptom experience at one and three months following the completion of initial cancer treatment, Beck et al, (2009) reported that this did not differ between rural and urban respondents. However, for a mixed methods study, their findings have limited generalisability with a small sample size (N=52). Equally so, the study tells us little about the longer-term (<5 years post-treatment) symptom experiences which this research was designed to do by including participants who were up to five years post-treatment (Chapter 4: 4.7.4 Participants).

In their study with people affected by cancer in America, Weaver et al, (2012; 2013) highlighted that rural survivors were more likely to self-report their health as fair or poor compared to their urban counterparts. They maintain that people affected by cancer in rural areas need tailored, and accessible health promotion interventions that have the potential to improve outcomes after a cancer diagnosis. Therefore, through understanding differences in self-management between rural and urban populations, the findings from this thesis have the potential to inform the design and delivery of support to people affected by cancer ensuring that these are tailored and in line with local and regional need. Health and Social Care services are increasingly incorporating robust research evidence to direct best practice and improve the coordination of care amongst different providers, departments and geographies. Finally, the concluding chapter of this thesis reports on some of the ways that the findings from this research have the potential to be utilised by key stakeholders to improve and inform existing services, as well as, supporting self-management in people affected by cancer (see Chapter 8: 8.4 Dissemination and Research Impact).

In sum, there is inconclusive or contradictory evidence when it comes to the role of rural-urban residency and its influence on the cancer experience. Whilst the needs of those in rural areas are well documented, particularly during the active treatment phase, and with specific types of cancer such as breast and prostate. That said, there is still limited evidence with regards to the longer term survivorship experiences and how whether where a person lives influences their ability to self-manage their health and health care following the completion of cancer treatment.

1.10 Project Monitoring and Steering Group

In terms of monitoring, the research process was overseen and quality assessed by three experienced supervisors from the School of Health and Social Care at the University of Lincoln. This involved monthly supervision sessions and the completion of progress reports that were signed off by an academic supervisor and submitted to the School Post-graduate Research (PGR) Team. An example of which can be found at Appendix 1. Additionally, the researcher had to complete and submit a PGR annual monitoring record that was reviewed and approved by the College Research Degrees Board. Again, on an annual basis, the researcher had to verbally present the research progress to fellow doctoral candidates and academic staff within the School of Health and Social Care at PGR annual presentation days. This facilitated a welcome opportunity where the researcher could receive constructive feedback from colleagues that was then used to inform and improve the thesis.

In addition to this, the researcher established and facilitated a Project Steering Group for the duration of the research. All three members of the supervisory team were active members of the Steering Group. The Group was complimented by senior staff from Macmillan Cancer Support and NHS Lincolnshire West Clinical Commissioning Group (CCG). Furthermore, there were two external academics, one from a different School and another from a different institution who had experience and expertise in cancer survivorship research. It was important to have someone from a clinical oncology background and so the Macmillan Lead Cancer Nurse from the local NHS acute trust participated in the Group. Moreover, a member of the public who had personal experiences as an individual who was diagnosed with cancer, as an informal carer, and as a local support group lead, volunteered to participate in the group (see Chapter 4: 4.2 Patient and Public Involvement (PPI) in the Research). In its final year, the Group was fortunate to have the input of the Research Impact and Knowledge Exchange Manager for the College of Social Science who influenced dissemination and research impact

activities (see Chapter 8: 8.4 Dissemination and Research Impact). The role and affiliation of all members is reported in Table 1.1.

Table 1.1 Members of Project Steering Group

Role	Organisation
Macmillan Partnership Manager Lincolnshire	Macmillan Cancer Support
Macmillan Partnership Quality Lead Lincolnshire	Macmillan Cancer Support
Macmillan Learning and Development Manager Midlands	Macmillan Cancer Support
Macmillan Lead Nurse for Cancer, Palliative and End of Life Care	United Lincolnshire Hospitals NHS Trust
Macmillan Cancer Development Manager	NHS Lincolnshire West Clinical Commissioning Group
Cancer Programme Manager	NHS Lincolnshire West Clinical Commissioning Group
Patient and Public Representative	No affiliation
Research Impact and Knowledge Exchange Manager	College of Social Science, University of Lincoln
Senior Nursing Research Fellow	Department of Nursing, Oxford Brookes University
Senior Lecturer	School of Sport and Exercise Science, University of Lincoln
Director of Research (Director of Studies)	School of Health and Social Care, University of Lincoln
Principal Lecturer (Academic Supervisor)	School of Health and Social Care, University of Lincoln
Honorary Research Fellow (Academic Supervisor)	School of Health and Social Care, University of Lincoln

Note: The membership of the group changed throughout the duration of the research and this list represents all those who participated at the time of study completion.

The researcher took responsibility for organising these meetings. The Project Steering Group met three times a year for the duration of the research at the University of Lincoln, Brayford Campus. The minutes were recorded for all meetings so that actions could be followed up and an example of these can be found at Appendix 2. The Group had a number of roles that are outlined below:

- To help guide and support the research from its early planning stages right through to dissemination and research impact activities.

- To provide expert advice to the researcher and troubleshoot on all appropriate aspects of the research.
- To update on the progress of the research, adherence to the study protocol, changes to study design, ethical clearance and dissemination activities.

1.11 Structure and Contents of Thesis

A doctoral thesis can be structured in a number of ways and is often dependent on the academic discipline as well as the institution at which the work is being conducted. In this research, the structure mostly adhered to what would be considered a 'conventional' PhD thesis. That is where an introductory chapter such as this current chapter (Chapter One) is followed by a review of the literature in the field (Chapter Two). This was then succeeded by the methodology (Chapter Three) and research methods (Chapter Four) that were utilised in the study. In some cases, the methodology and methods would be reported in the same chapter, however, in this thesis, it was felt that separating the two enhanced the readability and overall structure. Following the chapters in relation to methods, were a series of substantive chapters presenting the results from the research (Chapter Five and Six) which then informed the subsequent chapter that offered a discussion and interpretation of the findings as a whole (Chapter Seven). Given this study utilised an explanatory sequential mixed methods design (see Chapter 3: 3.7 Mixed Methods Research), the quantitative findings and qualitative findings have been reported on in individual chapters and then integrated in the discussion chapter that followed. Finally, in line with the conventional structure, this thesis finished with a concluding chapter (Chapter Eight) that summarised the study as a whole and offered a series of recommendation that were informed by the findings from the previous chapters. Overall, this thesis was divided into a total of eight chapters that are summarised in further detail below:

This introduction, **Chapter One**, has provided an overview of the context for this study by explaining the background to the field of self-management and how this has been contextualised within the cancer survivorship literature. Additionally, the rationale for the research and its contribution to existing knowledge have been presented, as well as, the aims and objectives of the study. Finally, the role of the Project Steering Group in overseeing the research was reported in this chapter.

Chapter Two provided a scoping review of the existing literature in the field of cancer survivorship in relation to self-management and rural-urban residency. The review question "What is known about the role of rural-urban residency in relation to self-management in people affected by cancer who have completed primary treatment? was utilised to steer the search strategy. The findings from the review identified a substantial gap in that the role of rural-urban residence had yet to be studied directly in relation to self-management following treatment for cancer with UK populations.

In **Chapter Three**, an overview of the quantitative, qualitative and mixed methods paradigms for conducting research were presented. Given this thesis and its underpinning research utilised quantitative, qualitative and mixed methods it was important to provide context to these different research paradigms as well as offering insight into the rationale behind adopting these approaches and how they were suited to answering the research question(s).

Chapter Four provided an overview of the research methods that were used to collect the primary data for this study, which aimed to compare self-management in people affected by cancer from rural and urban areas. An explanatory sequential mixed methods design was used where a quantitative self-completion questionnaire (N=227) was followed with a series of qualitative in-depth interviews (N=34).

Chapter Five presents the results from the self-completion questionnaire (N=227) that collected data from people affected by cancer in relation to demographics, health-promoting behaviours, patient activation, cancer related self-efficacy and free-text responses regarding further information in relation to self-management. The results in this chapter directly relate to the first four aims of the research (a) to identify and compare health-promoting behaviours in people affected by cancer from rural and urban areas (b) to identify and compare patient activation in people affected by cancer from rural and urban areas (c) to identify and compare cancer related self-efficacy in people affected by cancer from rural and urban areas and (d) to explore the relationship between health-promoting behaviours, patient activation and cancer related self-efficacy.

In **Chapter Six** the results from the analysis of the qualitative interviews (N=34) were reported and this was done utilising Braun and Clarke's (2006) six step approach to thematic analysis. The specific research questions answered in this chapter were: RQ5: What are the barriers and

facilitators to self-management in people affected by cancer? RQ6: Do the barriers and facilitators to self-management in people affected by cancer differ in rural and urban areas?

The purpose of **Chapter Seven**, the discussion, was twofold in that it firstly aimed to interpret the findings generated from the quantitative and qualitative data in line with the academic literature. Secondly, given the explanatory sequential mixed methods study design, it sought to further explain the quantitative differences identified between rural and urban participants utilising the data from the qualitative interviews. Through combining both quantitative and qualitative methods the researcher was able to provide richer answers to the primary aim of understanding differences with rural and urban populations in relation to self-management following cancer treatment.

The final chapter, **Chapter Eight,** provided a series of recommendations for people affected by cancer, healthcare professionals, policy makers and commissioners that were informed from the results of this thesis. In addition to this, concluding remarks regarding the research process and findings were reported at the end of this chapter.

1.12 Conclusion to Chapter

This introductory chapter has presented the contextual background and conceptual framework to this thesis, notably, the wider cancer survivorship and self-management literature that has informed this research. The rationale for the research was reported in that the research has contributed to the field of cancer survivorship and self-management by increasing our understanding of the rural-urban context in relation to cancer recovery following treatment. The research had a focused set of aims and objectives that were also reported on earlier in this initial chapter. This was succeeded by a summary of the structure and contents of the chapters that follow this initial chapter. Finally, this research was extremely fortunate to have been overseen and supported by a Project Steering Group and this chapter finished with a report on the role of this and how it informed the study. The following chapter provides a scoping review that aimed to map the existing peer reviewed academic literature that examined self-management in people affected by cancer who were post-treatment from rural and urban areas, as well as, serving to identify a considerable gap in the exiting evidence, that would justify the need for this thesis and its underpinning research.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction to Chapter

This chapter reports on the findings from a review of the existing academic literature that was pertinent to this thesis on self-management in people affected by cancer from rural and urban settings. This was completed utilising Arksey and O'Malley's (2005) five step framework for conducting a scoping review.

For Aveyard (2019), a literature review, in a broad sense, can be defined as the comprehensive study and interpretation of literature in relation to a specific field or topic. In this study, a literature review was a prerequisite to primary data collection in that it identified a gap in the evidence; informed the overall study design; subsequent analysis and finally, the interpretation of findings. However, it should be noted that this review was an ongoing process whereby the same keyword searches were performed at regular intervals (10/08/16; 01/08/17; 02/07/18; 23/07/19) throughout the duration of this thesis to ascertain any recently published literature in line with the research.

A literature review is frequently seen as a 'research method' in its own right (Aveyard, 2019) as evidenced by the rapid increase in published systematic reviews from the early 1990s to the present day. These have now become a fundamental component of health research that serves to influence clinical and healthcare decision making (Coughlan and Cronin, 2017). There are a range of terms to describe different types of literature reviews such as: narrative, integrative, scoping, realist, qualitative, rapid reviews, systematic, meta-analysis, meta-synthesis that are frequently utilised in the health and social sciences. According to Jesson et al, (2011) a narrative or 'traditional' literature review tends to explore issues, develop ideas and identify research gaps. Narrative reviews may or may not describe the methodology used to conduct the review. Conversely, a systematic review seeks to answer a specific review or research question utilising a predefined protocol with clear and transparent search criteria (Boland et al, 2017). Traditionally, systematic reviews have been concerned with reviews of effectiveness of interventions and answering questions about 'what works?' (Centre for Reviews and Dissemination, 2009). Therefore, they are frequently associated with answering more 'clinical' research questions that utilise quantitative data by incorporating evidence from randomised control trials (RCTs). However, as Coughlan and Cronin (2017) maintain, there has been an

increasing recognition that not all healthcare questions can be addressed by RCTs. That said, systematic methods or taking a 'systematic approach' is fast becoming best practice when conducting a literature review regardless of the framework that is utilised. Scoping reviews also differ from full systematic reviews in that they are rarely driven by a predetermined protocol (Armstrong et al, 2011). Nonetheless, the methods for a scoping review are usually reported in a transparent and comprehensive manner, similar to that of a systematic review. This is so the search strategy can be critiqued and/or replicated where appropriate. The methods for this scoping review are reported on in Section 2.4 'Methods for the Literature Review.'

2.2 Scoping Reviews

Whilst scoping reviews have been used for a number of years across a range of disciplines, Coughlan and Cronin (2017) maintain that they are a relatively new phenomenon in health and healthcare research. Within the existing literature there is little consensus as to what constitutes a scoping review (Boland et al, 2017) and they have been described in a range of ways, such as 'scoping studies', 'scoping method', 'mapping of research', 'rapid scoping reviews' and/or 'scoping projects' (Davis et al, 2009; Colquhoun et al, 2014). Nevertheless, the majority of scholars are in agreement that this method includes the concept of mapping out the evidence base in relation to a particular research question or subject area (Arskey and O'Malley, 2005; Levac et al, 2010) as was the case in the review reported on in this chapter.

Boland et al, (2017) outline the differences with some of the most common literature reviews: Firstly, a narrative review considers great breadth of information but in little depth. Conversely, a systematic review is typically narrow in the breadth of information considered but it examines the data in great depth. A rapid review can be as narrow, or in some cases, even narrower than a systematic review, but due to time constraints does not look at the material in as much detail. Finally, scoping reviews tend to be broader in scope than rapid reviews but do not go into as much depth as systematic reviews. In this study, a scoping review was considered the best approach as the research was not concerned with answering a clinical research question or looking at the effectiveness of an intervention which would have warranted the methods of a systematic review. Instead, the objective was to provide an overview of the existing research evidence in the field and identify any gaps that would precede and inform the primary data collection that is reported on in later chapters of this thesis (see Chapter 5 and Chapter 6). The extant literature points to a range of reasons (Anderson et al, 2008; Arksey and O'Malley, 2005;

Coughlan and Cronin, 2017) that support the adoption of this methodology and this is outlined below in Figure 2.1.

Figure 2.1 Reasons for Undertaking a Scoping Review

- To 'map' the extent, range and nature of research in a particular field.
- To determine the feasibility of undertaking a full systematic review or further empirical research.
- To summarise and disseminate research findings to academics, policy-makers, practitioners and consumers.
- To identify gaps in the existing literature.
- To develop methodological ideas and/or theoretical approaches that are suited to future research studies of a particular topic.
- To clarify conceptual understanding of a topic where definitions are unclear or where there is lack of agreement.
- To advise on and justify future research.

Adapted from Arksey and O'Malley, 2005; Anderson et al, 2008; Coughlan and Cronin, 2017.

2.3 Background

Prior to reporting on the methods (2.4 Methods for the Literature Review), results (2.5 Results) and discussion (2.6 Discussion) of the scoping review, further background to the research area, as a whole, and the review itself are provided. This was to provide the reader with a recap of the self-management and cancer survivorship literature that was initially provided in the introductory chapter (see Chapter 1). Furthermore, this offered an overview of the existing literature that did not explicitly examine self-management in relation to rural-urban residency, but instead, looked at other health outcomes, for example, health status and quality of life that were pertinent to informing this thesis.

2.3.1. Self-Management and Cancer Survivorship

The growing number of people living with and beyond cancer (Maddams et al, 2012) has seen cancer shift from being perceived as largely an acute illness to one that is now firmly situated within the framework for chronic and long-term conditions. Consequently, advances in early

detection, diagnosis and treatment of cancer present significant challenges such as long-term care and managing the side effects of diagnosis and treatment. At the same time, existing research indicates that the majority of people affected by cancer are interested in managing their own health and healthcare (Schulman-Green et al, 2011; Schulman-Green et al, 2012) as this offers them a sense of control (Schulman-Green et al, 2012). However, recent qualitative work by Corbett et al, (2018) suggested that some people do not intend to engage in lifestyle changes and that behavioural change, for them, in some cases was unnecessary in that they felt that non-modifiable factors contributed more to their cancer diagnosis than lifestyle related factors. Furthermore, there was uncertainty about how to implement adaptive changes and limited support from healthcare professionals. That said, for scholars such as McCorkle et al, (2011) self-management is significant at all stages of the cancer journey with a particular emphasis on the post-treatment phase as a result of reduced involvement with, and access to healthcare professionals. It is at this point where people affected by cancer can feel isolated and not sure where or how to access post-treatment support and resources. In addition, Foster et al, (2018) stress the growing recognition of symptoms and problems following cancer treatment and maintain that further research is needed to enhance understanding of experiences after treatment and to support self-management.

It is therefore not surprising, that people affected by cancer are increasingly self-managing the consequences of cancer long after treatment has ended (Foster and Fenlon, 2011) and they need support from health and social care professionals as well as the appropriate resources to facilitate self-management and ease the burden on primary care (Cavers et al, 2019). Notably, qualitative research in Australia (Hanks et al, 2008) emphasises the role that primary care and indeed, the General Practitioner (GP) need to play in rural and remote areas, to support self-management, where other specialist health services are often limited. There are now a range of interventions designed to support self-management with this population group (Gao and Yuan, 2011). However, an evaluation of cancer self-management interventions concluded that no one intervention can be recommended over another (Hammer et al, 2015) and that these need to be tailored to the health and cancer specific needs of particular individuals and groups. Indeed, many of these interventions focus on specific health behaviours such as exercise and diet (Lee et al, 2014), fatigue (Hoffman et al, 2013), or with particular tumour types such as prostate (Cockle-Hearne and Faithfull, 2010) and breast (Cimprich et al, 2005) as opposed to taking a holistic approach to self-management.

Whilst there is no 'gold standard' definition of self-management (Barlow et al, 2002) and it can mean different things to different people, within the context of cancer care, it has been described as approaches used by the individual affected by cancer (or life limiting illness) to optimise living (with the illness and its effects) which relates to 'self-management' as opposed to 'self-management support' (Foster et al, 2007). In the UK, the NCSI expanded on this further and defined cancer self-management as awareness and active participation by the person affected by cancer in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and well-being (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010).

Furthermore, existing cancer survivorship research in the UK by Shneerson et al, (2015a; 2015b) has classified self-management practices and strategies into the following six broad categories: (1) support groups (2) diet (3) exercise (4) psychological therapies (5) complementary and alternative therapies and (6) spiritual and religious practices. These categories were derived through a comprehensive review of the literature, as well as, extensive discussions with oncology health professionals, patient representatives, cancer support workers and complementary and alternative medicine researchers. Despite it being difficult to define and categorise, self-management, conceptually has become well established within the cancer survivorship literature over the last decade and research activity utilising a range of designs and methods is flourishing (Boland et al, 2018; Cimprich et al, 2005; Coffey et al, 2016; Davies and Batehup, 2010; Dunne et al, 2018; Foster and Fenlon, 2011; Foster et al, 2013; 2015; 2016; Gao and Yuan, 2011; Howell et al, 2017; Kim et el, 2017; McCorkle et al, 2011). This has been bolstered by the shift in perception that cancer is no longer an acute illness but one that requires long-term management long after active treatment has ended. Regardless, there is still no robust evidence that explicitly examines the role of rural-urban residency in relation to self-management in people affected by cancer who are post-treatment.

Whilst prolific UK cancer survivorship academics, Foster and Fenlon (2011), account for the role of environmental factors (e.g. social and community support) in their framework for recovery of health and wellbeing following cancer treatment (see Chapter 1: Figure 1.5) there is no explicit reference to the role of rural-urban residency, as an environmental factor that could potentially influence self-management, as well as, health and wellbeing. It has been documented that social and community support can differ greatly depending on where an individual resides (Reid-Arndt and Cox, 2010). Indeed, further qualitative work by Dunne et

al, (2018) on the barriers to self-management in people who had completed treatment for head and neck cancer found that access to appropriate health services and support was a perceived structural challenge to self-management, these are often things which we associate with distance and geography, however, there is no mention as to whether rural or urban geography had a direct impact on this.

2.3.2 Rural-Urban Residency and Health

Historically, the concept of urbanism and residing in a city were regarded as detrimental to psychosocial wellbeing (Milgram, 1970; Wirth, 1938). At present, more than fifty per cent of the global population are living in urban settlements and by 2030, urban areas are projected to house sixty per cent of the world's population, with one in every three people living in cities of at least half a million inhabitants (United Nations, 2016). The urban environment is frequently associated with increased rates of pollution (air, water, and noise), concentrations of lower socio-economic status, lower social capital, social segregation, and increased risk of physical threats (e.g. accidents, violence) all of which can pose as considerable risk factors to mental and physical illness (Gruebner et al, 2017). In addition, health inequalities tend to be greater in urban areas where there are a considerable number of areas that are concentrated with higher levels of deprivation and economically disadvantaged populations (Borrell et al, 2013). On the other hand, cities and urban areas frequently provide better access to medical care, employment and education (Gruebner et al, 2017) all of which have been shown to directly influence health and wellbeing with a range of populations including people affected by cancer. For Leon (2008), cities have long been at the forefront of commercial, scientific, cultural and political life. However, the positive and progressive aspects of urban living that have often been acknowledged by historians, academics and social scientists are often in contrast to the somewhat pessimistic view found in the epidemiological and public health literature.

For almost thirty years, academics have suggested that rural populations may have a distinct view of health that is different from non-rural populations (Gessert et al, 2015). In their influential paper on the health care needs of families, Weinert and Long (1987) postulated that rural people primarily associated health with "the ability to work", but were less prone to consider cosmetic, comfort or life-prolonging aspects of health as important (Gessert et al, 2015). Following this research, Weinert and Burman (1994) argued that this functional attitude to health possessed by rural people could contribute to delays in seeking and utilising health

care, even in the face of a serious or life-threatening illness. Further research by Davis et al, (1991) found that people from rural areas conceptualised health in terms of autonomy and self-reliance; they feared problems with or a decline in their health because it could lead to being a burden on others. Indeed, some of the literature that has succeeded this highlights that people in rural areas tend to be more stoic with regards to their health (Judd et al, 2006; Kroneman et al, 2010; Larson and Fleishman, 2003).

Much of the research on self-management in chronic conditions with regards to rurality suggests that place and context have a significant impact on health and illness (Cudney et al, 2005; Winters et al, 2006). Moreover, geographic isolation presents considerable challenges for those with chronic conditions, such as limited healthcare resources, the need to travel to access healthcare and its subsequent financial impact, and the physical and emotional isolation from others living with a chronic condition (Goins et al, 2005). Indeed, qualitative work by Sav et al, (2015) highlights that self-managing in a rural area requires much of the same lifestyle changes that are necessary in urban areas. However, the uniqueness of rural life and the limited availability of healthcare means that people in rural areas often need higher levels of organisation and planning, as well as, adopting more creative approaches when it comes to self-management. Furthermore, this resulted in high levels of self-reliance as well as looking to immediate family and social networks for support (Sav et al, 2015). Notably, geographic isolation can increase the burden of self-managing a chronic condition as well as providing considerable motivation to continue self-managing. People from rural areas often have to work with their environments and within the constraints of what is available to them. Rural activities can be used to replace those that are not available such as walking or running if they do not have access to a gym or fitness centre.

Furthermore, research by Winters et al, (2006) on rurality and self-management in women with chronic conditions suggests that rurality can influence self-management both positively and negatively. Positively, in that the availability of nature and green spaces, can promote health and wellbeing, as well as, access to peaceful and quiet environments that can be perceived as therapeutic and less stressful compared to those found in urban areas. Further positive aspects of rural living can be gained from activities such as crafts and gardening and access to outdoor recreation, most of these activities are performed with others which can establish strong social and community networks, as well as, rural values of helping others. At the same time, negatives

to rural living can involve feelings of emotional and physical isolation, traveling long distances for health services, amenities and to reach other people.

2.3.3 Rural-Urban Residency and Cancer Research

Whilst the rural versus urban debate has been well documented, the findings are inconsistent in that positives and negatives to both rural and urban living have been identified (Reid-Arndt and Cox, 2010; Rogers-Clark, 2002). Research with the general population has highlighted the benefits of rural living and 'green spaces' in terms of improving physical and mental health (Dhingra et al, 2009; Lankila et al, 2013; van den Berg, 2010; Verheij and Maas, 2008) and there are a range of characteristics belonging to rural communities that have the potential to benefit people affected by cancer (Reid-Arndt and Cox, 2010; Rogers-Clark, 2002). For example, rural communities frequently value close relationships with family and friends, community members and religious institutions (Bjorklund and Pippart, 1999; Kane and Ennis, 1996) which can all be significant sources of social support (Reid-Arndt and Cox, 2010) that are vital to coping with or minimising emotional distress when experiencing a traumatic life event such as a cancer diagnosis. For Reid-Arndt and Cox (2010), rural and urban areas can differ in the availability of social support that is delivered in the community. Indeed, qualitative work by Rogers-Clark (2002) identified the benefit of increased community support experienced by women affected by breast cancer who were living in rural compared to urban areas. Other researchers such as Gunn et al, (2019) reinforce the high levels of community trust in rural settings and suggest that future interventions need to be designed to capitalise on this.

Nonetheless, rural residents tend to have higher cancer mortality than urban residents (Carriere et al, 2018; Singh et al, 2011) and it has been well documented that people affected by cancer in rural areas face a range of additional challenges compared to their urban counterparts (Butow et al, 2012). For example, those in rural areas often have to travel longer distances for treatment, have limited access to medical care, support services, and health and social care facilities (Arcury et al, 2005; Beck et al, 2009; Noyes et al, 2017), are more likely to have unmet psychosocial needs (Butow et al, 2012; Harrison et al, 2009) as well as, being at increased risk for poorer health outcomes (Weaver et al, 2013) and poorer long term survival (Jong et al, 2004). Weaver et al's (2013) research on rural-urban disparities with US populations who had a history of cancer, found that when adjusting for age, gender, marital status, education, health insurance, time since diagnosis, and number of cancers that participants from rural areas were more likely to report fair/poor health, psychological distress, two or more co-morbidities and

health related unemployment. Other qualitative work by Howard et al, (2014) in rural Canada found that participants reported not having access to trusted and useful information, including financial and employment assistance. In addition to this, recent work in America by Zahnd et al, (2019) found that people in rural areas were more likely to report financial problems associated with cancer and its treatment compared to those in urban areas. Moreover, rural people affected by cancer may experience lack of symptom management, lack of access to psychosocial interventions, isolation (both geographic and emotional) and be less likely to cope with their situation (Hewitt et al, 2006). Further inequalities associated with residing in a rural area have been documented with cancer screening, diagnosis and treatment (Baade et al, 2011; Bettencourt et al, 2007; Mitchell et al, 2006). Additionally, cancer care requires sophisticated surgical and medical resources, as well as, highly skilled health professionals (Baldwin et al, 2008). These resources and skilled professionals are frequently found in urban areas or rural areas with larger populations as they require a tertiary hospital setting (Baldwin et al, 2008) thus putting those in remote areas at a disadvantage when it comes to accessing specialist support if they are not willing or perhaps unable to travel long distances. Despite the above evidence, Weaver et al (2012; 2013) contend that little is still known about rural-urban disparities that exist in the post-treatment and survivorship period.

In recognition of the challenges that rural residents, and specifically, people affected by cancer from rural areas face, Gray et al, (2019) recently examined whether rural and urban participants differed in their response to The Reach-out to ENhancE Wellness (RENEW) intervention. The aim of this home-based intervention was to improve a range of health behaviours and outcomes in relation to physical functioning, quality of life, fruit and vegetable intake, reduced saturated fat intake, body mass index (BMI), physical activity, and adverse events. The findings highlighted that the intervention lessened physical function decline overall and appeared to promote slightly better, if not comparable, effects in both rural and urban groups. At the same time, a lower proportion of rural versus urban reported smaller increases in fruit and vegetable intake, and lower percentages achieved their goals for endurance exercise and intakes of fruit and vegetables and saturated fat. Indeed, some of the existing literature from Australia (Gunn et al, 2019) highlighted that people affected by cancer from rural areas were more likely to be obese and physically inactive compared to those from urban areas. Nevertheless, this could be caused by deprivation as the difference disappeared when controlling for socio-economic disadvantage. At the same time, the findings are indicative that more research and further intensive lifestyle interventions are required to improve health and wellbeing, as well as, to

address and target disparities with this population group (Gray et al, 2019; Schootman et al, 2013; Weaver et al, 2013).

With regard to mental health, a quantitative study by Burris and Andrykowski (2010) highlighted disparities in people affected by cancer where those from rural areas reported poorer mental health outcomes compared to urban. Notably, those in rural areas reported greater anxiety and depressive symptoms, increased distress, more emotional problems, and poorer mental functioning than those living in non-rural areas. These differences were still significant in subsequent analyses that adjusted for differences in education and physical functioning. In their subsequent research, Andrykowski and Burris (2010) suggest that these disparities might result from differences in access to and utilisation of a range of formal and informal mental health resources where other studies have shown lower use of mental health resources in rural communities (Haunestein et al, 2006; Hauenstein et al, 2007). Interestingly, research has shown that people from rural areas are more likely to stigmatise mental health care, profess contempt for mental health professionals, and endorse an attitude of keeping their problems to themselves (Jackson et al, 2007; Wrigley et al, 2005). Despite the disparities in mental outcomes identified by Burris and Andrykowski (2010), results from their follow up study (Andrykoswki and Burris, 2010) indicated no widespread differences between rural and non-rural in mental health resource use, although some of their findings suggested poorer accessibility and less engagement with mental health professionals and cancer support groups within a rural setting. Notably, research by Gunn et al, (2019) found that people living in rural and urban areas were equally likely to report a mental health condition. Additionally, the response rate of thirty four per cent and relatively small sample size (N=116), given a quantitative design was utilised, raises concerns around the findings with regards to statistical power and sample representativeness in Burris and Andrykoski's (2010) study.

Other quantitative research, by Thomas et al, (2014) with people affected by head and neck cancer (N=583) in Ireland, highlighted that those in rural areas were more likely to report higher physical, emotional and head and neck cancer-specific quality of life than those residing in an urban area. Interestingly, these findings were at odds with existing studies on quality of life in cancer which reported a rural disadvantage (Butow et al, 2012; Burris and Andrykowski, 2010; DiSipio et al, 2010; Reid-Arndt and Cox, 2010). Notably, Thomas et al, (2014) maintain that more rural respondents were married or co-habiting compared to urban which could contribute to the higher scores. Furthermore, they point out that much of the existing literature

suggests that rural populations are more stoic with regards to their health, which again could have influenced the higher scores. Indeed, Butow et al, (2012) maintains that this could be a potential reason for differences and that rural population might be less inclined to ask for help and interestingly, recent research in Australia highlighted that people affected by cancer in rural areas were less likely to report higher levels of distress compared to those from urban areas (Gunn et al, 2019).

A recent large UK patient reported outcome study (N=35,823) with people affected by prostate cancer (Donnelly et al, 2019) highlighted that outcomes vary based on where people live in the UK. Additionally, Donnelly et al, (2019) found that quality of survival varied regionally in England when adjusting for treatment, clinical and sociodemographic factors. Whilst this is a substantive piece of work that offers valuable insight into survival amongst men with prostate cancer across the UK, the authors note that these inequalities merit further investigation. They suggest that these differences could be down to variations in population health, life expectancy, prevalence of comorbid conditions and socioeconomic status (Donnelly et al, 2019), however, they do not explicitly account for the role of rural-urban residency on these outcomes. Theoretically, the geographic residence of an individual may create another distinction which has important implications for self-management following cancer treatment. Therefore, this chapter, and this thesis, as a whole, aimed to specifically investigate the phenomenon of self-management in people affected by cancer who were post-treatment and to understand the role of rural-urban residency in relation to this.

2.4 Methods for the Literature Review

The methods for this review were based on Arksey and O'Malley's (2005) five step framework for conducting a scoping review. The five steps are (1) identifying the review question (2) identifying the relevant studies (3) selecting the studies (4) charting the data and (5) collating, summarising and reporting the results. Each individual step is reported on below in further detail and an overview of the methods and search strategy, as a whole, can be found in Figure 2.2. The adoption of this methodological framework ensured that the review process was methodical, rigorous and transparent (Coughlan and Cronin, 2017).

2.4.1 Identifying the Review Question

The first stage was to decide what the focus of the review was that would then subsequently steer the research strategy. The question "What is known about the role of rural-urban residency in relation to self-management in people affected by cancer who have completed primary treatment?" was developed to guide the search strategy. Initial scoping searches at the beginning of this thesis identified that this was an under-researched area and so this review question and subsequent search strategy sought to uncover the extent of work in this field prior to collecting and analysing primary data.

2.4.2 Identifying the Relevant Studies

According to Coughlan and Cronin (2017) parameters for searching should be decided at the outset, notably, in terms of time limit and language. There were no limits placed on the dates of publication when searching for articles, however, only studies in English could be included due to the researcher being a native English speaker and not having access to funds for translation. Other aspects, such as budget and time constraints may also limit the scope of the review although these were less salient concerns as this review was conducted as part of a doctoral thesis. Inclusion and exclusion criteria (see Table 2.1) were devised at the outset and refined again following initial searching.

The final string that was used to search was: (self-manage or "self manage" or self-management or "self management" AND cancer or neoplasms or oncology or tumour or tumor or malignancy AND surviv* or "living with cancer" or "living with and beyond cancer" or "affected by cancer" AND rural or remote or isolated or regional or "small town" or community or urban or cit*).

The databases searched were: Academic Search Complete, CINAHL, MEDLINE, PsycINFO, Scopus and Web of Science. This ensured that a wide range of databases relating to nursing, health and social care, mental health and the behavioural sciences were included. A summary of the contents of each database can be found in Table 2.2. Searches were run on the following dates: 10/08/16; 01/08/17; 02/07/18; 23/07/19. Additionally, supplementary searching was performed on Google Scholar throughout the duration of this thesis. Furthermore, PROSPERO, the International Prospective Register for Systematic Reviews and the Cochrane Library were searched to ascertain if there were any similar literature or systematic reviews that were ongoing or completed, in this case, there were not.

Figure 2.2 Summary of Scoping Review Methods and Findings

Review Question: What is known about the role of rural-urban residency in relation to self-management in people affected by cancer who have completed primary treatment?

Objectives:

- To map the existing peer-reviewed academic literature examining self-management in people affected by cancer who were post-treatment from rural and urban areas.
- To determine the extent and type of evidence available to inform more focused knowledge synthesis.
- To identify any gaps in the evidence for further research.

Inclusion/Exclusion Criteria

- Included: Peer-reviewed academic literature that reports primary research findings (quantitative, qualitative and mixed methods designs) on the role of rural-urban residency in relation to self-management in adults (≥ 18) affected by cancer who had completed primary treatment. English language. There were no restrictions on geographical location of the study or date of publication.
- Excluded: Studies that included people <18, participants who were currently undergoing active treatment, participants that were in receipt of palliative/end-of-life care, studies with no mention of rural-urban geography in relation to self-management. Research with carers/friends/family members/health and social care professionals. Studies that focus on diagnosis/screening/acute phase of treatment. Research with young adult/childhood cancer survivors (including late effects of childhood cancer) and parents of children with cancer. Studies that focused on self-management of other conditions – e.g. diabetes, heart failure, stroke. Study protocols, opinion pieces, conference abstracts. Not in English.

Search Strategy

Electronic databases: Academic Search Complete**,** MEDLINE, CINAHL, PsycINFO, Web of Science, Scopus Cochrane and PROSPERO (to check for existing reviews). Supplementary searching on Google Scholar.

Hand searches: Reference lists from retrieved literature.

Search Terms
self-manage or "self manage" or self-management or "self-management" AND cancer or neoplasms or oncology or tumour or tumor or malignancy AND surviv* or “living with cancer” or “living with and beyond cancer” or “affected by cancer” AND rural or remote or isolated or regional or "small town" or community or urban or cit*

Screening
Imported into EndNote X8. Screened by Title, Abstract and Full-Text against eligibility criteria.

Literature located
A total of nine studies met the eligibility criteria and were reported on in the results from the review.

Analysis
Data from included articles were extracted into an extraction form that collected data on authors, year of publication, study design, country, cancer type, study setting and findings in relation to self-management and rural-urban residency. Following this a descriptive synthesis was produced to map aspects of the literature identified in the review question/objectives.

Key Finding

- No studies offered direct insight into self-managing cancer within a rural-urban context in the UK.

Table 2.1 Inclusion and Exclusion Criteria

Criterion	Inclusion	Exclusion
Time period	Any	-
Language	English Only	Studies Published in Languages other than English.
Literature	Peer-Reviewed Academic Literature	Non Peer-Reviewed Academic Literature
Population	Adults who were 18 and over who had completed primary treatment for cancer.	Under 18; People currently undergoing active cancer treatment, people in receipt of palliative/end of life care. Studies exclusively on Family members/Carers/Health and Social Care Professionals
Study Focus	Report information on the experiences of self-management in survivorship in relation to rural-urban geography.	There is no data directly in relation to self-management and the influence of rural-urban geography.
Study Design	Quantitative, Qualitative and Mixed Methods Designs as well as relevant literature reviews.	-
Geographical location of Study	Any	-

Table 2.2 Overview of Databases Searched

Name of Database	Contents	Platform/Interface
Academic Search Complete	Multi-disciplinary journals, reports and proceedings.	EBSCO Host
CINAHL	Journals related to nursing and allied health issues.	EBSCO Host
MEDLINE	Journals related to life sciences, particularly biomedicine	Ovid, EBSCO Host
PsycINFO	Peer-reviewed journals related to mental health and the behavioural sciences	EBSCO Host
Scopus	Abstract and citation database of peer-reviewed research literature from scientific, technical, medical and social sciences fields and, more recently, also in the arts and humanities.	SciVerse
Web of Science	A multidisciplinary database containing journals related to medical and social issues among others.	Thomson Reuters
PROSPERO	Protocol details for systematic reviews relevant to health and social care, welfare, public health, education, crime, justice, and international development where there is a health related outcome.	www.crd.york.ac.uk/prospero/
Cochrane	Database of systematic reviews.	www.cochranelibrary.com/
Google Scholar	Academic literature across a range of publishing formats and disciplines.	scholar.google.com

2.4.3 Selecting the Studies

The researcher conducted the searches on four separate dates (10/08/16; 01/08/17; 02/07/18; 23/07/19). All of the databases that were searched were accessible via the University of Lincoln's library website (https://guides.library.lincoln.ac.uk/az.php). Firstly, a total of 438 articles were retrieved across the six primary databases (Academic Search Complete: N=89; CINAHL: N=50; MEDLINE: N=92; PsycINFO: N=40; Scopus: N=67; Web of Science: N=100) and exported into the reference management software EndNote X8. Furthermore, another three articles were retrieved from additional sources such as Google Scholar and reference lists from included articles. The duplicate articles (N=249) were removed leaving 192 articles that were first screened against the inclusion/exclusion criteria by title. A total of 59 articles did not meet the inclusion/exclusion criteria after title screening. Next, the abstracts were read for the remaining 133 articles and they were again screened against the study eligibility criteria. A total of 48 were taken forward for full text screening. Thirty nine articles were excluded following full text screening meaning that nine were included in the final review and reported on in the results. The main reason for articles being excluded at full text screening was down to them not reporting any data that directly referred to the role of rural-urban residency on self-management (N=28). Some of the other reasons for exclusion were down to study participants undergoing active treatment (N=7) or it was not clear if the participants in the articles had completed primary treatment yet (N=4). The search process is reported on in Figure 2.3: Flow Diagram of Scoping Review.

2.4.4 Charting the Data

The next stage of Arksey and O'Malley's framework involved charting the data according to an analytical framework that facilitated sorting the material into relevant themes (Coughlan and Cronin, 2017). Therefore, standard information such as authors, year of publication, study setting, aim, methods, study population, findings in relation to self-management and residency were collected from all included articles. Collecting this information helped to answer the review question: "*What is known about the role of rural-urban residency in relation to self-management in people affected by cancer who have completed treatment?"* The data that were extracted for each individual study can be found in the completed table at Table 2.3.

Table 2.3 Data Extraction Table

Authors	Year	Setting	Aim	Methods	Participants	Findings
Adams, N., Gisiger-Camata, S., Hardy, C. M., Thomas, T. F., Jukkala, A., & Meneses, K.	2017	Alabama, USA.	To better understand unique rural AA-BCS survivorship experiences and needs in the Alabama Black Belt.	Qualitative (Focus Groups/Interviews) Survey used initially for demographic and treatment data.	African American Breast Cancer Survivors (n=15)	- Importance of social support from friends/family and healthcare providers. - Lack of survivorship education in the rural setting. - Participants identified needs for information about survivorship self-management, in particular around managing treatment related side effects. - Spirituality and religion were prevalent coping strategies.
Gisiger-Camata, S., Adams, N., Nolan, T. S., & Meneses, K.	2016	Alabma, USA.	Community-based participatory research and multi-level assessment were used to (a) engage rural community leaders, survivors, and providers; (b) analyze and report results of discussion groups to understand survivorship concerns and preferences; (c) integrate discussion group findings to develop, tailor, and deliver Reach Out; and (d) evaluate Reach Out with regard to satisfaction and helpfulness	Mixed Methods 16 Discussion Groups with RBCS	Rural Breast Cancer Survivors (n=16)	- Self-management concerns: (1) fatigue (2) pain (3) depression (4) lymphedema (5) bone health osteoporosis (6) hair loss (7) sexual function (8) hot flashes and menopausal symptoms and (9) comorbidities - Fears around being lost in transition, preferences around cancer support and concerns about cancer surveillance and health.
Glasser, M., Nielsen, K., Smith, S. N., & Gray, C.	2013	Illinois, USA.	the purpose of this study was to collect information to better understand the psychosocial needs of rural survivors of cancer and their significant others. The	Quantitative (Survey)	Rural Cancer Survivors (n=29) and Partners (n=15)	- Over half at risk for depression and 34% reported some psychosocial problem that needed managing – side effects or complications from treatment, emotional support or the impact of cancer on social relationships. - Those in rural areas need a team approach to meeting psychosocial needs.
Lally, R. M., Eisenhauer, C., Buckland, S., & Kupzyk, K.	2018	Nebraska, USA.	To obtain rural breast cancer survivors' perceptions of the quality and usability of CaringGuidance™ After Breast Cancer Diagnosis, a web-based, psychoeducational, distress self-management program; and explore the feasibility of	Primarily Qualitative (online focus groups) Did collect some demographic and quant. data	Rural Breast Cancer Survivors (n=23)	- Practical to recruit and retain rural people affected by cancer for research and testing of an intervention. - Rural willing to participate with digital technologies for self-management (emotional distress)

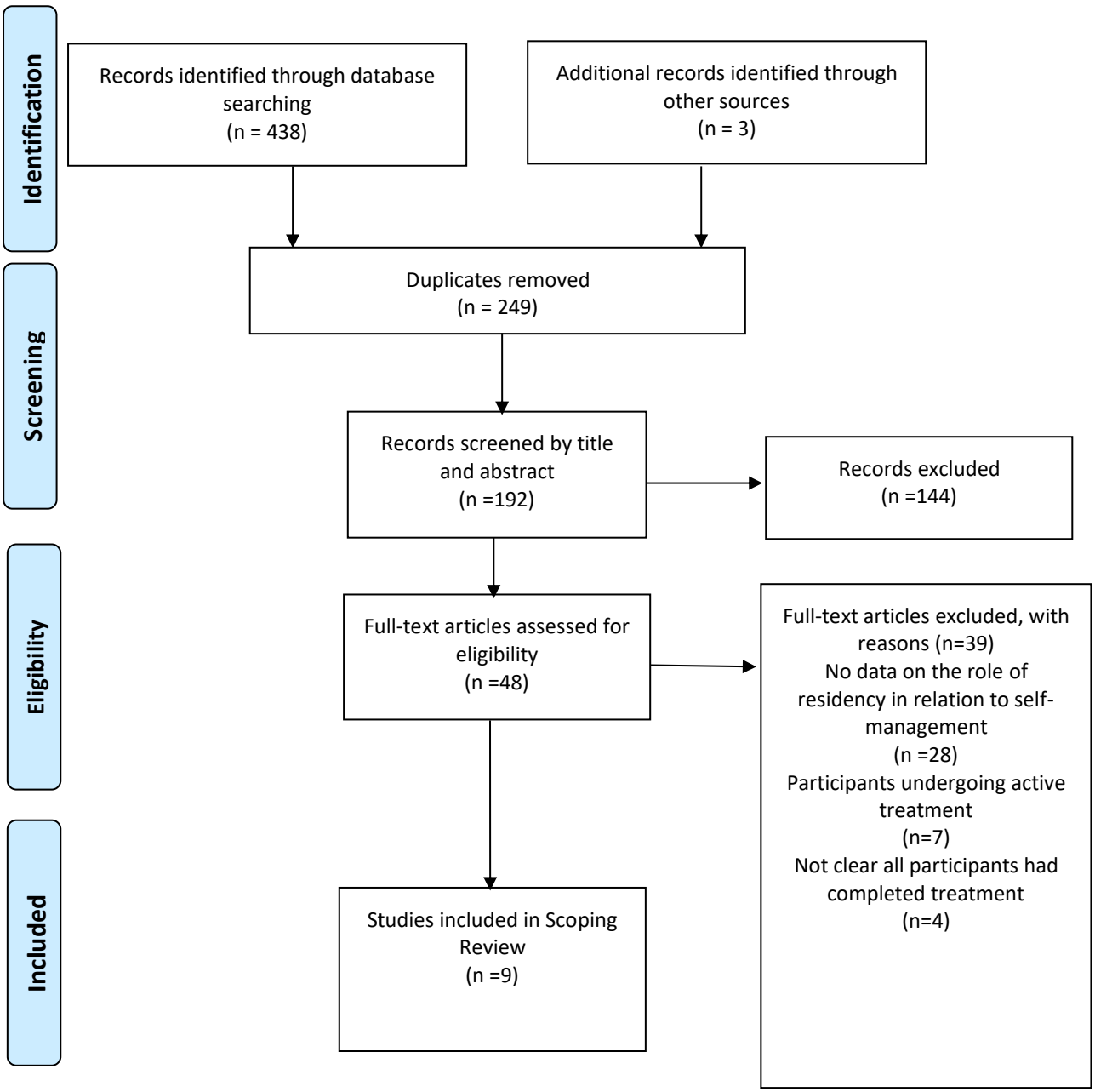
			gathering survivors' perceptions about CaringGuidance™ using online focus groups (OFG)s.			- Challenges negative findings around rural internet use.
Lawler, S., Spathonis, K., Masters, J., Adams, J., & Eakin, E.	2011	Australia (range of locations classed as 'rural').	To explore and examine experiences and perceptions of follow-up care (medical and psychosocial) after active treatment for breast cancer among women living outside major Australian cities.	Qualitative – Telephone Interviews	Rural Breast Cancer Survivors (n=25)	- Limited access to medical follow up care, psychosocial and lifestyle support programmes in rural settings. - Lack of community-based support programmes was a key concern. - Some participants given information about support that was not available in their area. - Desire for peer support – some proactive in seeking this using telephone and the internet.
Loudon, A., Barnett, T., & Williams, A.	2017	Tasmania, Australia.	To describe the experiences of women taking part in a yoga intervention trial for breast cancer-related lymphoedema.	Qualitative - Interviews	Rural Breast Cancer Survivors (n=15)	- Holistic practices like yoga can be successful in the rural setting. - Participants reported improved wellbeing, increased awareness of their body, as well as, improved physical, mental and social functioning. - Intervention also provided an opportunity to share experiences and for peer support.
McNulty, J. A., & Nail, L.	2015	Pacific Northwest,USA	To compare the impact of cancer in rural- and urban-dwelling adult CSs living in 2 regions of the Pacific Northwest.	Mixed Methods	Cancer Survivors Quantitative (N=132) Qualitative (N=19)	- Significant differences between rural and urban in quant. data. - The interview highlighted further differences in relation to accessing health care, care co-ordination, connecting/community, thinking about death and dying, public/private journey, and advocacy. - Rural participants tended to advocate for themselves, their diagnosis, survivorship, and for improved health care in their communities.
Purtzer, M. A., & Hermansen-Kobulnicky, C. J.	2013	Wyoming, USA.	The study objective was to examine the meaning of self-monitoring practices within the context of rural patients' responses to internal and external information.	Qualitative – semi-structured interviews	Cancer Survivors (n=20)	- Cognitive, affective, interpersonal, and symptomatic) that informed self-monitoring which subsequently facilitated a sense of control and self-advocacy. - Cognitive – collected and critically appraised info they were given, note taking and recording information they were given was helpful.

						- Affective – fear anxiety and frustration but these negative feelings facilitated a desire to learn about cancer and manage it. - Interpersonal factors (informal and health professionals) vital to learning about cancer, treatment side effects and self-management in general. - Symptomatic – adverse treatment side effects. - Rural reported active coping strategies as opposed to 'passive'
Stephen, J., Rojubally, A., Linden, W., Zhong, L., Mackenzie, G., Mahmoud, S., & Giese-Davis, J.	2017	British Columbia and Yukon, Canada.	The study aims were to examine proof of concept—feasibility, acceptability, and usefulness—and to hone methods for a formal RCT.	Mixed Methods Feasibility study with Qual Component	Breast Cancer Survivors (n=105)	- Rural women benefited from online support group with psychoeducation more so than urban areas. - The group supported self-management and facilitated focused and meaningful discussions that reduced illness related stress.

2.4.5 Collating, Summarising and Reporting the Results

Following, charting of the data, the final stage was to collate, summarise and report the results of the included studies. According to Coughlan and Cronin (2017) scoping reviews provide a descriptive account of the available research and do not normally attempt to appraise the literature utilising a quality assessment tool such as the CASP (Critical Appraisal Skills Programme) checklist. An overview of the included studies is reported on below (see 2.5 Results from the Scoping Review).

Figure 2.3 Flow Diagram of Scoping Review



2.5 Results from the Scoping Review

A total of nine articles that met the study eligibility criteria were included in the review (Adams et al, 2017; Gisiger-Camata et al, 2016; Glasser et al, 2013; Lally et al, 2018; Lawler et al, 2011; Loudon et al, 2017; McNulty and Nail, 2015; Purtzer and Hermansen-Kobulnicky, 2013; Stephen et al, 2017). The studies were published from 2011-2018 and conducted in the USA (N=6), Australia (N=2) and Canada (N=1). Out of the nine articles, four used qualitative methods, four used a mixed methods design and one was conducted using solely quantitative methods. Five of the studies were with people affected by breast cancer and the other four included participants who had been affected by a range of cancers.

Adams et al's, (2017) qualitative study with African American women from rural Alabama who had been affected by breast cancer (N=15) highlighted the need for social support from family and friends, as well as, healthcare providers. They highlighted a lack of survivorship education and support in their area. Furthermore, participants identified their needs for information about survivorship self-management, notably, around managing treatment related side effects. Within this context, spirituality and religion were crucial to coping with a cancer diagnosis and the effects of its treatment.

Further qualitative research (Purtzer and Hermansen-Kobulnicky, 2013) utilising semi-structured interviews with adults from a rural state in Western America who had completed treatment for cancer (N=20) found four factors (cognitive, affective, interpersonal, and symptomatic) that informed self-monitoring which subsequently facilitated a sense of control and self-advocacy. Self-monitoring can be considered a specific self-management strategy that involves patient awareness of thought processes, activities, and physical symptoms in addition to the measuring, observing, recording and tracking of signs and symptoms. In terms of cognitive factors, participants collected and critically appraised the information that they were given. Some participants found note taking and recording information helpful to keeping track of and managing their situation. Information came from a range of sources such as health professionals, family, friends, support groups and the internet. Affective factors involved feelings of fear, anxiety, frustration, uncertainty and helplessness. However, these negative emotional responses facilitated a desire to learn about cancer and how best to manage it. Interpersonal relations were vital to learning about cancer, treatment side effects and self-management in general. For some, these were limited to interactions with only health

professionals whereas for others these extended to reliance on friends and family, support groups. Finally, the symptomatic factor refers to adverse treatment side effects and participants would keep track and document these in the hope of minimising or managing them better in the future. For the most part, these rural participants reported 'active' coping strategies as opposed to 'passive' although there were no comparisons made to those from urban areas.

A recent feasibility study by Lally et al, (2018) highlighted that it is practical to recruit and retain people affected by breast cancer from rural areas for online focus groups and testing of a web-based education and self-management programme. The study is evidence that rural women are willing to participate in online focus groups and use web-based self-management support. Indeed, this was endorsed as an appropriate self-management tool for managing emotional distress and Lally et al, (2018) maintain that knowing this is important to overcoming negative perceptions about rural internet use and this could be a suitable strategy to improve rural mental health disparities.

Further mixed methods research by Stephen et al, (2017) with young women (<50) who had a diagnosis of breast cancer indicated that women who were from semi-rural and rural areas benefited from an online support group with psycho-education more so than those from urban areas. Moreover, the online support group that was professionally led supported self-management and facilitated focused and meaningful discussions that reduced illness related stress. Notably, the study was also successful in outreach efforts to rural and semi-rural locations that normally lack psychosocial services and self-management support compared to their urban counterparts.

A qualitative study by Loudon et al, (2017) examined a yoga intervention as a tool to facilitate self-management with a sample of rural Australian women (N=15), who had experienced lymphoedema as a consequence of treatment for breast cancer. The participants were highly motivated as evidenced by their high level of compliance regardless of having to travel for an hour and a half to attend the yoga sessions. However, the small sample size raises questions as to whether this would be replicable to a larger sample. That said, holistic therapies such as yoga offer a range of practices that can be tailored according to the needs of the individual. Participants reported improved wellbeing, increased awareness of their body, as well as improved physical, mental and social functioning. The intervention also provided a place for them to share experiences with their peers. For Loudon et al, (2017) yoga has the potential to

augment and provide additional benefit to current self-management and treatment practices for women with breast cancer-related lymphedema.

Gisiger-Camata et al, (2016) report on the delivery and development of the Reach Out to Rural Breast Cancer Survivors initiative that was delivered within a rural setting in four rural counties in Northeast Alabama in the United States. Four major concerns were highlighted through content analysis of discussions with sixteen women who were post-treatment, one of these major concerns being self-management in survivorship. The other three major concerns were fears around being lost in transition, preferences for support and concerns about cancer surveillance and health. The authors then identify a further nine themes from the data that they suggest relate to self-management concerns: (1) fatigue (2) pain (3) depression (4) lymphedema (5) bone health osteoporosis (6) hair loss (7) sexual function (8) hot flashes and menopausal symptoms and (9) comorbidities. These themes were then used to inform the content of the Reach Out intervention. For example, practical self-management tips on how to locate local resources were integrated into the programme, as well as, specific tips to address sexuality and intimacy issues.

Glasser et al, (2013) conducted a pre-tested survey to ascertain general and mental health, quality of life and demographics with rural people who were diagnosed with cancer and were not undergoing any active treatment (N=29) as well as, their partners (N=15). Specifically, in relation to the findings of people with a personal history of cancer, over half were at risk for depression and 34 per cent reported some type of psychosocial problem that required assistance, such as management of treatment related side effects or complications of treatment, emotional support or the impact of cancer on social relationships. The authors suggest that those in rural areas likely require a team approach to meeting psychosocial needs

In their qualitative study (N=25) on experiences of follow-up care (medical and psychosocial) following breast cancer treatment for women living outside major Australian cities, Lawler et al, (2011) highlighted that there was limited access to medical follow-up care, as well as psychosocial and lifestyle support programmes in rural settings. Interestingly, lack of community-based support programmes was a key concern, and some participants were given information about support that was not available in their areas. Several participants wanted peer support with other women affected by cancer, some were proactive in sourcing this in the local area, using the telephone and internet to access this. Furthermore, there should be greater

co-ordination of care between health professionals to improve communication and reduce the burden on both, the patient and the medical system.

Finally, McNulty and Nail's (2015) mixed methods study compared the impact of cancer in rural and urban dwelling adults in two regions of the Pacific Northwest. This involved a questionnaire (N=132), as well as, in-depth interviews (N=19). The results show statistically significant differences between rural and urban when it comes to differences in body concerns, worry, negative impact, and employment concerns. The interview data indicated further differences in relation to accessing health care, care co-ordination, connecting/community, thinking about death and dying, public/private journey, and advocacy. Rural participants tended to advocate for themselves, their diagnosis, survivorship, and for improved health care in their communities. The advocacy emerged as seeking a second opinion, accessing support resources, asking questions and seeking answers and fighting for their financial and employment rights. The rural participants in particular engaged with community advocacy by fundraising, volunteering with survivorship organisations and speaking publicly about survivorship issues.

2.6 Discussion

Firstly, none of the studies that met the eligibility criteria, offered direct insight into self-managing cancer within a rural-urban context in the UK. Similar to much of the broader literature on survivorship and geography (Bettencourt et al, 2007; Butow et al, 2012; Pascal et al, 2015; Weaver et al, 2012; 2013) the included studies were conducted in the United States, Canada and Australia. Whilst the studies that were included in this review shed light on some of the self-management experiences within a rural-urban setting they are from countries with different healthcare systems and services in comparison to the UK, thus warranting further investigation in a UK setting. Despite the increasing body of work that explicitly focuses on self-management and cancer within a UK context (Davies and Batehup, 2011; Foster et al, 2015, Foster et al, 2016; Henshall et al, 2017; Henshall et al, 2018; Shneerson et al, 2015a; Shneerson et al, 2015b) there are no studies that have reported data on rural-urban residency in relation to this. Equally, research comparing outcomes between rural and urban people affected by cancer has tended to focus on the post-diagnosis stages, as well as survival rates and has yet to examine the influence of residency on longer-term survivorship outcomes, such as, self-management post-treatment.

Interestingly, all nine articles used some form of qualitative methods, either in isolation or in combination with quantitative methods as a mixed methods design. Qualitative methods seem an appropriate choice to shed light on and explore the in-depth experiences of people affected by cancer, however, there is a considerable need for larger studies with increased sample sizes that utilise quantitative and mixed methods designs. Particularly, where geography is concerned, there is a need for research with a range of cancer types over several different regions so the results can be generalisable to wider rural and urban populations. Much of the research that was included focused on one specific location, with relatively small sample sizes, and in some cases with the same cancer type such as breast (N=5) which limits the extent to which the findings can be inferred to other settings and population groups.

Only two of the included studies collected data from participants in urban areas, as well as, rural (McNulty and Nail, 2015; Stephen et al, 2017). Whilst these two studies identified some of the similarities and differences with rural and urban populations in relation to 'self-management' they do not explicitly focus on 'self-management' as one of the primary variables under investigation. Indeed, self-management studies that compare between rural and urban with people affected by cancer are non-existent within the UK and international literature. With that in mind, researchers in psychosocial oncology should be encouraged to collect both quantitative and qualitative data on rural-urban residency to enhance their analyses. Whilst the studies in this review that focus directly on rurality signpost to the perceived differences with rural and urban living when presenting their background and context, they do not collect and analyse data from urban populations in their own study which limits the extent to which we can consider these findings unique to the rural setting without a comparator group. Some of the existing American cancer research that has compared between the two on mental health (Burris and Andrykowski, 2010), health status and health behaviours (Weaver et al, 2012; 2013) has used official statistics to categorise and define rural-urban residence and other researchers, where appropriate, should be supported to do the same. In fact, utilising the same methods for defining and measuring rural-urban status would support comparison between researchers, at the very least, on a national and regional level and promote wider collaboration in the field. Furthermore, interventions needs to account for geography and the specific traits of rural and urban populations, therefore, cancer survivorship scholars should be encouraged to take note of this when designing and implementing interventions.

With regard to the findings from the studies themselves, they identified the salient needs of those from rural areas and that emotional management seems to be a significant concern (Glasser et al, 2013). This is not surprising given that geographic and emotional isolation is often associated with rural living as seen in some of the wider literature (Goins et al, 2005; Hewitt et al, 2006). However, in contrast, Gisiger-Camata et al, (2016) maintains that survivorship experiences are similar regardless of rural-urban residence with the exception of access to specialised survivorship services and resources being the primary difference, as well as, a considerable challenge for those in remote locations. A potential solution could be the use of IT and Lawler et al, (2011) suggests that digital technologies and e-health applications have the potential to support and address needs with rural populations who have been affected by cancer. That said, for this to work it would be dependent on internet access which can still be limited (or even non-existent) in very rural and remote locations. Indeed, recent work in the UK by Brett et al, (2018) with people affected by breast cancer suggests that an e-health app could be successful in facilitating peer support and coping strategies. At the same time, research by Corbett et al, (2018) maintains that social networking does not always provide added benefit and consideration needs to be given to what stage of the cancer journey this is delivered to the individual. With that in mind, if future time and financial resources are to be invested in the design and utilisation of digital technologies to support health behaviours and self-management, academics and health professionals have a duty to ensure that these are designed and tailored to the needs of both rural and urban populations.

The findings from McNulty and Nail (2015) highlighted some of the differences and similarities between rural and urban and the authors themselves maintain that their findings serve to challenge the widespread assumption about rural living and its perceived negative impact on health outcomes. Notably, some of the wider literature reinforces a range of characteristics belonging to rural communities that have the potential to benefit people affected by cancer (Reid-Arndt and Cox, 2010; Rogers-Clark, 2002). Perhaps not surprisingly, a common theme from McNulty and Nail's data was 'community' and their findings show that access to health care might not be the most salient concern when it comes to the survivorship experience. Foster and Fenlon (2011) account specifically for social and community support in their framework for recovery of health and wellbeing in cancer survivorship and it has been posited that community support can differ depending on where an individual resides (Reid-Arndt and Cox, 2010). This study sheds light on the role of empowerment in rural communities and future researchers in the field should take note. However, the majority of their sample were

female and had been affected by a breast cancer diagnosis where there might be more resources available to support recovery and self-management. Nonetheless, the findings highlight some interesting traits of rural communities in relation to cancer survivorship that warrants further data collection with more diverse samples.

Given a scoping review is not meant to be exhaustive but serves to offer the reader with a good sense of the literature it is possible that some relevant publications were not included. Regardless, the number of included articles (N=9) serves to illustrate that this is an under researched area, particularly with UK populations, who have completed primary cancer treatment. To date, there is no existing research that examines and compares self-management with people affected by cancer who have completed treatment in rural and urban parts of the UK. Specifically, there are no studies, that have examined and compared the quantitative outcomes that were utilised in this thesis (HPLP-II; PAM-13; CSSES) with people affected by cancer who had completed treatment from rural and urban parts of the UK (see Chapter 5). In addition, the qualitative phase of this study explored and compared, the barriers and facilitators to self-management in people affected by cancer who had completed treatment from rural and urban parts of the UK (see Chapter 6). Again, there are no existing studies that have explicitly focused on this. If rural and non-rural populations define their health in different ways as some of the literature suggests then efforts to support self-management in both populations will need to be better informed by robust evidence given the increasing focus on patient centred care (Gessert et al, 2015). It is therefore important to consider if residency can be a predictor of self-management, as well as, what acts as a barrier and/or facilitator to self-management, the findings can then be used to inform support that is delivered to people affected by cancer and ensure that it is tailored to population needs in line with geography. For that reason, the subsequent chapters of this thesis outline the methods and findings that tackled this substantial gap within the extant literature.

2.7 Conclusion to Chapter

This chapter has presented the findings from a scoping review that sought to answer the review question: *What is known about the role of rural-urban residency in relation to self-management in people affected by cancer who have completed treatment?* This was conducted utilising Arksey and O'Malley's (2005) framework for performing a scoping review. After title, abstract

and full text screening, the nine articles that met the study eligibility criteria have highlighted a gap in the field that warranted further investigation through collecting primary data. Much of the literature around residency and cancer has tended to focus on the active treatment phase as opposed to longer-term survivorship outcomes such as self-management. Given the plethora of research on rurality in cancer it is surprising that survivorship academics have not yet investigated this in relation to self-management. The results from this scoping review should act as considerable indication of the lack of research activity in this specific field. Indeed, the pressing need for well-designed robust studies that collect quantitative and qualitative data from both rural and urban populations that have been affected by cancer. Therefore, this mixed methods research collected primary data to better understand the influence of rural-urban residency on how people affected by cancer manage their health and health care following treatment. The results of which are reported on in Chapter 5 and Chapter 6. However, first the methodology (see Chapter 3) and research methods (see Chapter 4) that were utilised to inform and conduct the study are reported on in the subsequent chapters.

CHAPTER THREE: METHODOLOGY

3.1 Introduction to Chapter

This chapter provides an overview of the quantitative, qualitative and mixed methods paradigms that were applied in this thesis. The term paradigm was given its contemporary meaning by the philosopher of science Thomas Kuhn in his influential text *The Structure of Scientific Revolutions* (Kuhn, 1962). In this context, it refers to the beliefs, assumptions, values and practices shared by a research community, and it provides an overarching framework for conducting research unique to that paradigm. Over several decades and into the twentieth century, Kuhn's research paradigm construct has been utilised by a range of academic and non-academic fields where it has become firmly established as part of the lexicon of social and scientific research (Donmoyer, 2006). According to Punch (2014) paradigms should answer three interrelated questions that highlight the connections between research methods and the underlying philosophical issues: (1) what the reality is like (ontology); (2) what the relationship is between the researcher and that reality (epistemology); and what methods can be used for studying the reality (methodology).

Given this thesis and its underpinning research utilised quantitative, qualitative and mixed methods it was important to provide context to these different research paradigms as well as offering insight into the rationale behind adopting these approaches and how they were suited to answering the research question(s).

Firstly, the specific research questions that the research aimed to answer using quantitative, qualitative and mixed methods are outlined below. This is followed by an overview of epistemology and ontology which are two different ways of considering a research philosophy and a summary of quantitative, qualitative and mixed methods research as applied in this study.

3.2 Research Question(s)

The research aim was generated to outline what the study set out to achieve and a set of focused aims and questions gave direction and purpose to the study In this case, the primary aim was **to investigate and compare self-management in people affected by cancer following treatment from rural and urban areas.**

The research questions were developed following the literature review (see Chapter 2) which highlighted an evidence gap , notably, a lack of research on rural-urban residency and whether this impacted on self-management following cancer treatment. It is common practice to conduct a comprehensive literature prior to collecting primary data to inform decisions around the methodological approach. The research question should narrow the problem into a more concise statement (Moule, 2018) and this research sought to provide a comprehensive answer to the following primary research question: **what are the differences in self-management in people affected by cancer following treatment from rural and urban areas?**

The primary research question was then broken down into specific sub-questions that warranted different methods of inquiry. The questions relating to health-promoting behaviours, patient activation, and cancer-related self-efficacy were concerned with identifying and comparing differences in both rural and urban populations and warranted the use of quantitative methods (see 3.3 Quantitative Research) utilising a self-completion questionnaire with people affected by cancer, the results of which are reported in Chapter 5.

The specific research questions were as follows:

- *Research Question 1:* What are the differences in health-promoting behaviours in people affected by cancer from rural and urban areas?
- *Research Question 2:* What are the differences in patient activation (knowledge, skills and confidence to manage health and health care) in people affected by cancer from rural and urban areas?
- *Research Question 3:* What are the differences in cancer-related self-efficacy (belief that one can successfully execute behaviour required to produce expected outcome in relation to consequences of cancer and its treatment) in people affected by cancer from rural and urban areas?
- *Research Question 4:* Is there a relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy?

The second phase of data collection which aimed to explore and compare the barriers and facilitators to self-management was concerned with the in-depth examination of what helped or prevented people from managing their health and whether where they lived influenced this. The exploratory nature warranted qualitative methods (see 3.4 Qualitative Research) of inquiry

and used individual in-depth interviews with people affected by cancer. The results from this phase of the study are reported in Chapter 6. The specific research questions for this phase of the research were as follows:

- *Research Question 5:* What are the barriers and facilitators to self-management in people affected by cancer?
- *Research Question 6:* Do the barriers and facilitators to self-management differ in rural and urban areas?

The research adopted a mixed methods approach (see 3.7 Mixed Methods Research) to data collection. Prominent mixed methods scholars such as Creswell and Creswell (2018) consider it best practice for researchers who utilise mixed methods designs to incorporate a mixed methods question into their studies to convey the importance of integrating or combining the quantitative and qualitative components. This is the question that will be answered based on the mixing of both types of data (Creswell and Plano Clark, 2018) and is what Tashakkori and Creswell (2007) call a "hybrid" or "integrated" research question. This is vital because mixed methods do not solely depend on quantitative or qualitative methods in isolation but on both forms of inquiry (Creswell and Creswell, 2018). Therefore, the mixed methods research question for this study was as follows:

- *Research Question 7:* How does the qualitative interview data on barriers and facilitators to self-management further explain any quantitative differences identified with rural and urban populations?

Through combining both quantitative and qualitative methods the researcher was able to provide richer answers to the primary aim of understanding differences with rural and urban populations in relation to self-management following cancer treatment.

3.3 Epistemology

Epistemology is the branch of philosophy that deals with the theory of knowledge and was the invention of post-enlightenment Western philosophy arising from two distinct traditions (1) rationalism and (2) empiricism (Williams, 2016), the former referring to an epistemological

position that posits that knowledge can be established through the use of human reasoning and the latter which emphasises experience in the acquisition and testing of knowledge (Benton and Craib, 2001). The 'rationalist' view was influenced by the methods of mathematics which attempts to arrive at 'absolute' truths through formal reasoning. Conversely, for the rival 'empiricist' the sole source of knowledge comes from our senses and is accumulated through learning. According to Benton and Craib (2001), the empiricist view of knowledge is the one most natural and social scientists adhere to when making their claims to provide genuine or definitive knowledge. Additionally, they contend that it is also the view of knowledge that is closest to the majority of people's common-sense intuitions, for example, 'seeing is believing' or 'I saw it with my own eyes.'

In scientific and social research what constitutes 'knowledge' and how we derive meaning from the world have instigated a number of contentious debates (Delanty and Strydom, 2003) and within social science research, epistemology is frequently used to indicate the philosophical underpinnings of methodology and it can relate to both the knowledge and assumptions underlying the researcher's chosen research approach, as well as, those of the research participants (Williams, 2016).

3.4 Ontology

Ontology is the study of existence and the nature of things that exist with particular consideration as to what constitutes reality (Williams, 2016) where epistemology is concerned with knowledge and belief about reality. For Williams (2016), epistemology is about *how* we know, and ontology is about *what* we know. Historically, ontology has been classed as a sub-component of the branch of philosophy known as metaphysics that examines the nature of reality (van Inwagen, 2001).

Social researchers such as Blaikie (2007) maintain that there are three general (although by no means exclusive) ontological positions: (1) realism (2) idealism and (3) empiricism. Realists believe the assumption that there is an underlying reality in our social world, one that we can not necessarily observe but is somewhat partially knowable. This contrasts with idealism where the world is made up only of representations which are created by our individual minds. In this respect, what we class as 'reality' is a collective social creation and because that is all we can know, nothing can be derived beyond this. As an academic discipline philosophy was primarily

divided between realists and idealists until around the 17th century, when the third ontological position of empiricism emerged through the work of British philosopher, John Locke (1690). As previously mentioned, for empiricists, the only legitimate claims to knowledge are those that can be established by inference to sense data (Benton and Craib, 2001). Thus, all our knowledge about the social world comes from the interaction of our five senses with the world. Idealism and empiricism contend that there is only 'sensation', but for the idealist sensation is internal in that it relates to the mind, whereas for empiricists sensation is external, it is stimuli. For the Scottish philosopher, David Hume (1711-1776), whose work has influenced much of the development of the methodology of quantitative methods (see 3.5 Quantitative Research) in social research, these stimuli are not attributed to actual physical things, but a manifestation of our psychology to process these stimuli (Williams, 2016).

3.5 Quantitative Research

In the broadest sense, quantitative research refers to collecting data that are numerically based and amenable to statistical analysis, often in relation to hypothesis testing (Barker et al, 2019; Walliman, 2016). For Punch (2014), quantitative research essentially does three things. It (1) conceptualises reality in terms of variables, (2) measures these variables and, (3) studies relationships between these variables. In this study, the quantitative phase aimed to collect variables in relation to self-management and cancer survivorship that could be measured numerically and compared between rural and urban respondents using statistical techniques.

The quantitative method of inquiry uses deductive reasoning, meaning the researcher works from one or more statements (premises) and through logical argument, comes to a specific conclusion (Sternberg, 2009). Deductive logic is therefore informed by the theory that precedes it. In science, theories are speculative answers to perceived problems that can be tested by a predefined protocol of observation and experiment (Walliman, 2016). Conversely, inductive reasoning makes broad generalisations from specific observations (Williams, 2016). For example, repeated observations of only white swans, using inductive logic, could lead us to the generalisation that "all swans are white" and that no other colours of swan exist (Magee, 1982). However, there is no scientific reasoning behind this generalisation only habit or prejudice for expecting that all swans everywhere will in fact be white (Benton and Craib, 2001).

In quantitative research, to test a theory, that theory needs to be expressed as a hypothesis. A hypothesis is an informed speculation about the potential relationship between two or more variables (Bryman, 2008). For the philosopher of science, Karl Popper (1961), a strong and scientific hypothesis must be falsifiable meaning that it must be logically possible to make true observational statements that conflict with the hypothesis that could falsify it. Returning to the example with the white swans, although no number of observations of white swans should allow us to derive the universal statement that "all swans are white", one single observation of a black swan, allows us to logically derive the statement "not all swans are white" (Magee, 1982). In this sense our empirical generalisations about the world are not verifiable, they are falsifiable.

Hypotheses can take two forms: (a) null and (b) alternative (Creswell and Creswell, 2018). A null hypothesis makes a prediction that no relationship or significant difference exists between groups and the wording is "There is no difference (or relationship)" between the groups. The alternative or 'directional' hypothesis makes a prediction about the expected outcome that is informed by the existing literature. For example, we might hypothesise that "Rural participants will have greater engagement with health-promoting behaviours than urban participants."

In this study, the following null hypotheses were derived in relation to each of the specific quantitative research questions (Research Questions 1-4):

- *Null Hypothesis 1:* There is no significant difference in health-promoting behaviours in people affected by cancer from rural and urban areas.
- *Null Hypothesis 2:* There is no significant difference in patient activation in people affected by cancer from rural and urban areas.
- *Null Hypothesis 3:* There is no significant difference in cancer-related self-efficacy in people affected by cancer from rural and urban areas.
- *Null Hypothesis 4:* There is no significant relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy.

A significant body of social science research utilises methods drawn and influenced from the natural sciences (Bowling, 2014). This approach is known as positivism and it recognises that only two forms of knowledge have claims to the 'true' status of knowledge, the empirical and the logical: the former represented by natural science and the latter by logic and mathematics

(Hughes, 1990). The positivist approach emphasises the importance of testing, measuring and achieving scientific truth, which might be seen as a 'universal law' (Moule, 2018). For positivists, the truth can be accessed through 'controlling' variables for cause-and-effect relationships and they claim that all our ideas about the world are formulated through sensory experience.

Positivism is frequently associated with quantitative methods whereas interpretivism is likely to be associated with qualitative methods (Punch, 2014) and is discussed later in this chapter. Positivism is centred around the hypothetico-deductive method and the idea of falsification outlined above (Gomm, 2009). According to Bryman (2008), positivism entails the following five principles: (1) only phenomena and hence knowledge confirmed by the senses can genuinely be warranted as knowledge; (2) the purpose of theory is to generate hypothesis that can be tested and that will allow explanations of laws to be assessed (deductivism); (3) knowledge is arrived at through the gathering of facts that provide the basis for laws (inductivism); (4) science must (and presumably can) be conducted in an objective and value-free way and (5) there is a clear distinction between scientific statements and normative statements and a belief that the former are the true domain of the scientist. Although as Williams (2016) contends, few social researchers firmly adhere to all the principles of positivism in their strongest form with very few defending the idea that we can have a truly 'value free' approach to social science research. Philosophers such as Popper (1961) and Kuhn (1962) have been advocates of positivist methods in their quest for objectivity and independence between the researcher and participant, however, they have also been critical of positivism by recognising the potential effects of biases. This in turn has influenced the development of 'post-positivist' or 'post-empiricist' philosophy which pursues objectivity through experimental methods but acknowledges that existing theories, knowledge and values have the potential to influence what is observed (Delanty and Strydom, 2003). For the 'true' positivist, quantitative methods are the only tool, whilst the post-positivist will give equal consideration to both quantitative and qualitative methods (see 3.6 Qualitative Research) depending on the research question.

Traditionally, the majority of social science has developed in line with positivist philosophy, alongside the physical sciences (Bowling, 2014). In quantitative studies, some of the most common positivist or post-positivist approaches to study design use surveys (de Vaus, 2013) and experimental methods (Berg and Latin, 2008), and then analyse the data utilising statistical

techniques, as was such in this study (see Chapter 4 4.7.9 Statistical Analyses). In addition, positivism has influenced many of the methods of research on health and health care, and the way research instruments are administered (Bowling, 2014). For example, most quantitative questionnaires and surveys are standardised and structured in order to minimise the influence of the instrument (Choi and Pak, 2005) and the interviewer on the respondent (Lavrakas, 2008). Furthermore, there has been a strong emphasis on experimental research such as randomised control trials (RCTs) where the researcher aims to introduce a treatment or intervention to study causal relationships (Barker et al, 2019).

Quantitative research can also have a non-experimental design where the research is used to identify associations between variables. Non-experimental designs can be cross-sectional where data are collected at a single point in time (Gomm, 2009) or they can be longitudinal where data are collected over a period of time (Walliman, 2016). Additionally, they can be retrospective where data that have been collected in the past are examined (Moule, 2018). Prospective studies are another form of non-experimental design where data are collected in relation to a specific independent variable and the dependent variable is measured at a later date (Baker et al, 2019).

The first phase of data collection in this study used a cross-sectional design utilising survey methods that collected data from a sample of people affected by cancer at a single point in time (reported on fully in Chapter 4). This was done using a self-completion postal questionnaire (see Appendix 3). This meant that a number of numeric scales (HPLP-II; PAM-13; CSSE) that were identified through the existing literature could be utilised to identify quantitative differences in rural and urban populations and to answer the research question(s) (Research Questions 1-3).

There were a range of advantages to this method in that the data generated could be utilised to prove and/or disprove the null hypotheses. Cross-sectional studies allow information to be gathered on a multitude of variables at the time of data collection of which the findings and outcomes can then be used to inform subsequent data collection, in this case the qualitative interviews. The use of a self-completion questionnaire meant that it could be posted to a large number of people across a wide geographical area (Moule, 2018) in this case people were sent a questionnaire with a primary focus on the East Midlands region of England. This method accommodated participants in that it allowed them to complete the questionnaire anonymously

in the comfort of their own home or another location of their choosing at a time that was convenient to them (Walliman, 2016). Furthermore, this method allowed results to be made available relatively quickly and there were no problems of decreasing participation with loss to follow up, that can occur in longitudinal studies that collect data on at least two occasions over a prolonged period of time (Robinson and Seale, 2018).

3.6 Qualitative Research

Historically, in many of the social sciences, quantitative methods have been regarded as superior to qualitative methods in that their more 'scientific' and positivist (or post-positivist) approach to research has long been considered a more credible tool to social inquiry by the public and policy makers (Berg, 2007). These two competing schools of thought have traditionally been regarded as polar opposites, with the quantitative paradigm represented by positivism, and the qualitative based on interpretivism and constructivism (Gray, 2018). However, the 'quantitative versus qualitative' debate has diminished in recent times, with the increasing popularity and utilisation of qualitative and mixed methods (see 3.7 Mixed Methods Research) research designs. Qualitative researchers are consistently adopting more 'systematic' and 'scientific' approaches to data collection (e.g. theoretical sampling) and analysis (e.g. content analysis; thematic analysis) which have only strengthened the external perception of the discipline and its associated methods. There has also been a marked increase in Computer Assisted Qualitative Data Analysis Software (CAQDAS) such as ATLAS.ti, Dedoose, QDA Miner and NVivo (Silver and Lewis, 2014) which are used to enhance the management and analysis of qualitative data. In this study, the qualitative software package NVivo (Ver. 11) was used to systematically code and thematically analyse (Braun and Clarke, 2006) the qualitative interview data (see Chapter 4: 4.8.4 Qualitative Data Analysis).

Qualitative research tends to, although not exclusively, use language or textual data that are written or oral (Green and Thorogood, 2018) as opposed to quantitative research that utilises numerical data and analyses them using statistical techniques (Walliman, 2016). At the same time, the distinction between textual and numerical data should not be seen as mutually exclusive to the quantitative or qualitative paradigm as many qualitative studies use frequency counts, whereas textual data can also be used to enhance quantitative studies. For example, in this research an open-ended question that collected qualitative data was used at the end of the quantitative questionnaire to encourage respondents to reflect on and add to their responses to

the quantitative measures that were used in the previous sections (see Appendix 3; Section 5: Further Information). In primarily quantitative studies, researchers such as O'Cathain and Thomas (2004) have endorsed the use of such qualitative questions to optimise the quality of data and enhance the overall analysis which informed the rationale for using a free text box at the end of the self-completion questionnaire. This can be considered a type of 'mixed methods' (see 3.7 Mixed Methods Research) where researchers are utilising qualitative responses to better understand answers to quantitative questions. Additionally, this approach has been adopted specifically with populations of people with a cancer diagnosis in England (Corner et al, 2013; Wiseman et al, 2015), Wales (Bracher et al, 2016) and more recently Scotland (Cunningham and Wells, 2017) where qualitative comments have been utilised in national patient experience and patient reported outcome surveys that also collect quantitative data.

Qualitative approaches are associated with the interpretivist paradigm (McEvoy and Richards, 2006) and this philosophy in contrast to positivism, sees our social world as a multiple, constructed, interdependent whole that cannot be broken down into measurable segments (Grbich, 1999). Thus, we cannot 'quantify' or 'categorise' individual experience and feelings in the way that a positivist researcher might aim to, through the use of survey methods. The interpretivist believes that through interpreting and drawing meaning from the social world, it can be understood (Moule, 2018). In summary, qualitative research is attempting to generate and analyse data that comprises of words and images to gain an in-depth understanding of a particular social phenomena. This research collected audio data via interviews that was later transcribed into text that aimed to explore individual perceptions, experiences and behaviours of people affected by cancer in relation to self-management and where they lived.

A further distinguishing feature of qualitative research is that it studies people in their 'natural' or everyday environments rather than artificial or experimental ones (Green and Thorogood, 2018; Pope and Mays, 2006). Out of the many qualitative approaches, ethnographic methods are perhaps viewed as the most 'naturalistic' in that they generate in-depth knowledge about a specific setting (e.g. hospital ward or GP surgery) where the researcher observes participants as well as becoming part of that setting for a period of time (Green and Thorogood, 2018). Another one of the most frequently used naturalistic research methods, the in-depth interview was utilised to collect qualitative data in this study. In this method, the researcher talks to those who have knowledge of or experience with the problem of interest (Rubin and Rubin, 2012). In this case, it was people affected by cancer who had completed treatment and resided in both

rural and urban areas. This allowed the researcher to explore in greater detail the experiences, motives and opinions of people affected by cancer in relation to how they managed their health and health care. This was in line with existing research (Henshall et al, 2017) that used qualitative interviews to understand how and why self-management practices were incorporated into the lives of people affected by cancer. In this study, the majority of participants who took part in the qualitative component were interviewed in their private home (with their advanced consent) which can also be considered a 'natural' setting. As opposed to a clinical or public setting, this offered comfort and convenience where people were more inclined to talk openly and honestly regarding their experiences of self-managing cancer.

Some of the most frequently used methods in qualitative research include participant observation, individual and group interviews (focus groups), analysis of text or documents and the analysis of recorded speech or behaviour using audio or visual equipment (Pope and Mays, 2006; Saks and Allsop, 2013). Again, the research was concerned with the in-depth individual experiences of self-management and so did not warrant the analysis of documents or the collective views of a group that could have been generated through focus group data. Unstructured (also referred to as in-depth or open-ended) and semi-structured interviews have a number of advantages over structured questionnaires and survey research. According to Low (2013), these methods are best utilised when it comes to accessing experiences of health and illness where people may feel disempowered by their condition, such as, cancer. As discussed above, quantitative research sets out to test a particular hypothesis in relation to a specific research question. The interpretivist or constructivist perspective utilising qualitative methods adopts an inductive approach that provides access to the subjective perceptions of participants, as well as the means by which they give meaning to their experience (Low, 2013). For example, in this study, a structured questionnaire was used to provide context for the qualitative data by providing demographics, frequencies of health-promoting and self-management behaviours in people affected by cancer, as well as, identifying differences between rural and urban respondents. At the same time, the structured questionnaire tells us less about the individual experience of people affected by cancer and what helps or prevents them from managing their health. To do this, an in-depth discussion between the researcher and participant was required, that then subsequently generated rich qualitative data that could be analysed in relation to the research question (Research Questions 5 and 6).

Themes and concepts were developed from an interpretation of the observational, interview data (Moule, 2018) with people affected by cancer. Whilst there are a range of analytical approaches to qualitative data, the common focus is on talk and action as opposed to numbers. Some of the most common approaches to qualitative data analysis include content analysis, discourse analysis, grounded theory, narrative analysis and thematic analysis. In this study, Braun and Clarke's (2006) approach to thematic analysis was utilised to analyse the qualitative data. This reflexive approach consists of six phases and is outlined in the subsequent chapter (see Chapter 4: 4.8.4 Qualitative Data Analysis). As a "method", thematic analysis first appeared in the 1970s but was frequently adopted inconsistently (Braun and Clarke, 2014). It was through the work of Boyatzis (1998) that laid the groundwork for a more systematic approach to coding and theme development. For Boyatziz (1998), thematic analysis can be considered a translator for those speaking the languages of qualitative and quantitative analysis, enabling researchers who use different methods to communicate with one other. Consequently, Boyatiziz would later influence the widely used method for thematic analysis in the social and health sciences that was developed by Braun and Clarke (2006) in their seminal paper *Using Thematic Analysis In Psychology*. Braun and Clarke (2014) maintain that the "in psychology" part is now widely disregarded, and the method has been used extensively across a range of academic disciplines which frequently have a health focus.

Whilst there are similarities with this method and other types of thematic analysis such as Interpretative Phenomenological Analysis (IPA), the end result can often be similar particularly when working with small samples. At the same time, IPA provides a complete framework for conducting research (Biggerstaff and Thompson, 2008) whereas thematic analysis is solely a method or technique for collecting and analysing data (Braun and Clarke, 2006). The same can be said for grounded theory which in itself is a methodology with an inbuilt theoretical framework (Strauss and Corbin, 1994). Furthermore, IPA is dependent on the sampling strategy (homogenous, small N) and this research aimed to collect qualitative data from a diverse and large sample of people affected by cancer.

Equally, content analysis and thematic analysis can be similar, or they can be very different dependent on how the researcher makes sense of and uses these methods (Hsieh and Shannon, 2005). Similar to thematic analysis, content analysis is regarded as a method as opposed to a methodology and is frequently understood as atheoretical with positivist assumptions utilising coding reliability measures (Potter and Levine-Donnerstein, 1999). However, for Braun and

Clarke (2013; 2014) qualitative analysis can never be atheoretical and researchers always make theoretical assumptions whether acknowledged or not, therefore, they advocate the use of thematic analysis over content analysis as it is considered a theoretically flexible method.

The qualitative phase of this research aimed to explore, and compare, the barriers and facilitators to self-management in people affected by cancer from rural and urban settings. This component of the research was conducted to understand more about the phenomenon of self-management and cancer survivorship from the perspectives of the individuals who were directly affected by a cancer diagnosis and treatment.

3.7 Mixed Methods Research

Together with quantitative research and qualitative research, mixed methods are considered by some as the third primary research approach or research paradigm (Johnson et al, 2007). One of the core assumptions is that statistical trends (quantitative data) are combined with stories and personal experiences (qualitative data), and this collective approach provides a better understanding of the research problem than either quantitative or qualitative methods could alone (Creswell, 2015; Morgan, 1998). However, not all scholars would support mixed methods as a distinct research paradigm maintaining that quantitative and qualitative paradigms incorporate incompatible assumptions about how we understand and study the social world (Sale et al, 2002). Furthermore, Gorad (2010) maintains that mixed methods are not a design or represented by paradigms and that rather than considering quantitative and qualitative paradigms as opposing binary forces, consideration should be given to the design and full cycle of research work. Therefore, the adoption of quantitative, qualitative and mixed methods is not seen as a distinct research approach or worldview but more as a suitable way to undertake a study dependent on the research problem and question.

To reiterate, in this study, several research questions were identified through the existing literature that warranted quantitative (Research Questions 1-4) and qualitative (Research Questions 5-6) methods of inquiry. However, to provide an answer to the primary aim and research question these methods needed to be combined (Research Question 7) and interpreted in unison (see Chapter 7) in order to better understand the differences with self-management in rural and urban populations with a history of a cancer diagnosis.

As an identifiable methodology, Creswell and Plano Clark (2018) date the beginning of mixed methods to the late 1980s. It was during this time that a range of researchers from different disciplines and countries were sketching out an approach that moved beyond simply using quantitative or qualitative methods in isolation. They were giving significant consideration for ways to link or combine these methods, as well as, how to integrate or mix data (Creswell and Plano Clark, 2018). As a discipline, mixed methods has been experiencing significant growth as evidenced by the expanding body of literature and the launch of several academic journals (e.g. *Journal of Mixed Methods Research, Quality and Quantity* and the *International Journal of Multiple Research Approaches*) as well as the proliferation of research articles across a number of disciplines reporting on research utilising mixed methods designs (Lewis, 2014) including several studies in the cancer survivorship field (Bender et al, 2016; Klassen et al, 2018; McNulty and Nail, 2015; Scarton et el, 2018; Shneerson and Gale, 2015).

Perhaps the most commonly associated philosophical position that is associated with mixed methods is that of pragmatism. It traces its beginnings to the American philosophers Charles Sanders Peirce (1878), William James (1907) and John Dewey (1938) who are considered the 'classic pragmatists' (Webb, 2007). Pierce is frequently referred to as the "the father of pragmatism", James its translator to a wider audience, and Dewey as its most well-known advocate based on his influential work in education and social reform (Gray, 2018). According to Morgan (2014), classic pragmatism is considered a theory of truth where meaning cannot be given in advance of experience. As opposed to considering reality or truth in relation to traditional metaphysics, this emphasis on human experience, which was inherently contextual, emotional, and social, was at odds with the established philosophy of the time (Morgan, 2014).

In recent decades, in social research, there has been increasing attention on pragmatism, as a result of providing an epistemological position for mixing approaches and methods (Onwuegbuzie et al, 2009; Johnson and Onwuegbuzie, 2004). As classic pragmatism sought to break down the dualism between realism and idealism, it remains highly pertinent to social research (Morgan, 2014) and some of the more recent pragmatists include Patton (1990), Rorty (2000) and Tashakkori and Teddlie (2003). At the same time, some of the neo-pragmatists like Rorty, reject correspondence of truth in any form, which a considerable number of philosophers would disagree with (Johnson and Onwuegbuzie, 2004). Furthermore, criticisms of pragmatism include the promotion of incremental change as opposed to more fundamental, structural, or revolutionary change in society, studies failure to provide information on who a

pragmatic solution is useful for, and the ambiguous explanation of what is meant by usefulness or workability (Johnson and Onwuegbuzie, 2004).

For the pragmatist, rather than being bound by the parameters of positivist or interpretivist methods of inquiry, there is an emphasis on flexibility and choice of research methods to match the aims of the study, and in some cases to the needs of the setting where the research is being conducted (Creamer, 2018). The pragmatic position is that these, rather than philosophical assumptions should drive operational choices about how to design and conduct research (Creamer, 2018; Gorad, 2010). Consequently, it is not surprising that mixed methods, a discipline and method that embraces a range of approaches is associated with this philosophical position. Again, for the pragmatist, the theory-driven 'deductive' approach and data-driven 'inductive' approach are not so much in conflict, they are two distinct approaches to research, that we can move between and this is considered 'abductive' reasoning where the method is selected on what is appropriate for the setting (Johnson and Onwuegbuzie, 2004).

From an ontological perspective, Johnson and Onwuegbuzie (2004) maintain that pragmatism avoids theories about the nature of truth and reality and places explicit emphasis on what is practical and what works given the circumstances. With that in mind, the research process should be considered somewhat open and fluid where researchers can adapt and are susceptible to change where and if necessary. Furthermore, from an epistemological position, the quality of research is judged by usefulness, utility, or transferability. Therefore, with regard to the utility and transferability of health and social care research, the findings should strive to explicitly inform, complement, and improve at least one of the following: (1) practice; (2) policy; (3) healthcare professionals; (4) services and (5) service users.

It is important to note that a range of mixed methods definitions exist depending on the philosophical stance of the author (Johnson et al, 2007) with varying levels of specificity. In Johnson et al's, (2007) analysis of nineteen mixed methods' definitions, there is mostly agreement that quantitative and qualitative research is what is mixed. For some, the mixing takes place at the data collection phase, others at analysis, or during both data collection and analysis. Scholars such as Yin (2006) have been explicit in their argument that mixed methods must include quantitative and qualitative perspectives of the same research question although this view is not unanimous amongst mixed methods academics. Indeed, in this study, that was not the case as the research questions were dependent on different methods. Finally, definitions

differ on the many reasons why mixing is carried out and this can be for a singular or multiple purpose (e.g. breadth/depth and corroboration or to simply meet the aims of the research project).

For Creswell (2015, p.2) and in this thesis, the focus was on mixed methods as a **method**, in which data collection, analysis and interpretation take centre stage, therefore, mixed methods is defined as:

> *"An approach to research in the social, behavioural, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative (open-ended) data, integrates the two, and then draws interpretations based on the combined strengths of both sets of data to understand research problems."*

Given the multitude of definitions and approaches to mixed methods (Johnson et al, 2007) that exist, it is hardly surprising that much like quantitative or qualitative research design, there is no fixed or universal guidance when it comes to designing a mixed methods study. However, Creswell et al, (2011) have put forward useful guidance that was utilised to steer the design, data collection, analysis, integration and writing up stages of this study. This is presented in Figure 3.1 and the corresponding chapters where this has explicitly informed the content are reported on.

Figure 3.1 Guidance for Conducting Mixed Methods

Preliminary considerations:

- Philosophy and theory. **See Chapter 1: Introduction and Chapter 3: Methodology.**
- Resources (e.g. Time, financial resources, skills) **See Chapter 1: Introduction and Chapter 4: Research Methods.**
- Research problem and reasons for using mixed methods. **See Chapter 1: Introduction; Chapter 2: Literature Review and Chapter 3: Methodology.**

❖ State study aims and research questions that call for quantitative, qualitative, and mixed methods, and incorporate your reasons for conducting a mixed methods study. **See Chapter 1: Introduction and Chapter 3: Methodology.**

❖ Determine methods of quantitative and qualitative data collection and analysis (when it will be collected, what emphasis will be given to each, and how they will be integrated or mixed). **See Chapter 4: Methodology and Chapter 4: Research Methods.**

❖ Select a mixed methods design that helps address your research questions and the data collection/analysis/integration procedures. **See Chapter 3: Methodology and Chapter 4: Research Methods.**

❖ Collect and analyse the data. **See Chapter 5: Questionnaire Results and Chapter 6: Interview Results.**

❖ Interpret how the combined quantitative and qualitative approaches contribute to addressing the research problem and questions. **See Chapter 7: Discussion.**

❖ Write the final findings making explicit the contribution of the mixed methods approach. **See Chapter 8: Conclusion and Recommendations.**

Adapted from Creswell et al (2011, p. 6-7).

For mixed methods researchers, Curry and Nunez-Smith (2015), there are three primary mixed methods designs that are frequently used in health sciences research: (1) convergent; (2) exploratory sequential and (3) explanatory sequential and these are outlined in Table 3.1 below.

Table 3.1 Mixed Methods Research Designs

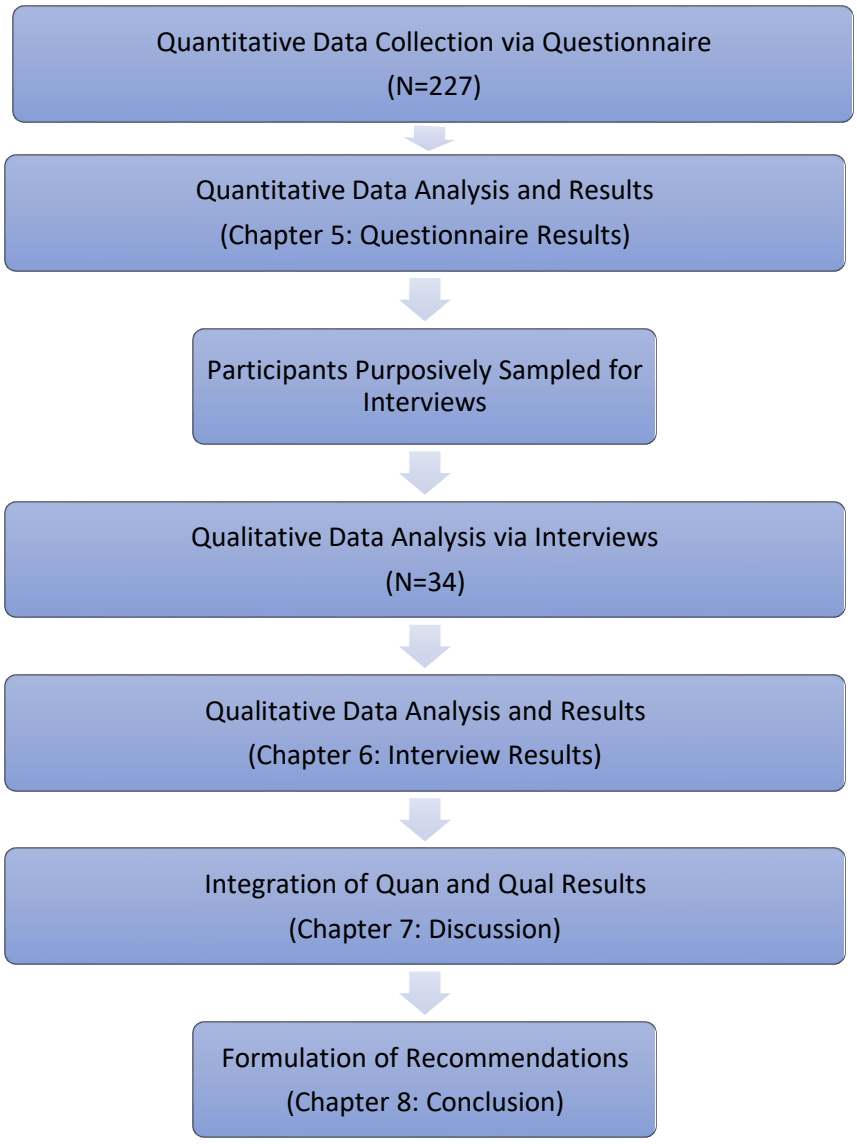
Design	*Overview*
Convergent design	• The aim of research is to collect both quantitative and qualitative data. • Analyse both datasets individually and then merge the results of the two with the purpose of comparing the results (validating one set of results with the other).
Exploratory Sequential Design	• The aim is to first explore a research problem with qualitative methods. • The researcher uses qualitative findings to build a second quantitative phase of the project which might involve designing an instrument to measure variables or an intervention. • Third phase, the quantitative instrument or intervention are used for quantitative data collection and analysis.
Explanatory Sequential Design	• First phase involves quantitative data collection. • The second phase which involves qualitative data collection following the quantitative data collection helps to explain the quantitative results in more depth.

Adapted from Creswell (2015); Creswell and Creswell (2018); Curry and Nunez-Smith (2015)

In this study, the explanatory sequential mixed methods design was utilised (see Figure 3.2) because it involved two phases of data collection in which the researcher collected quantitative data first via a self-completion questionnaire (see Chapter 4: 4.7.8 Questionnaire Design and Appendix 3), analysed the results and then used the results to inform the second phase of qualitative data collection. This meant that the quantitative results could inform the types of participants to be purposefully selected for the qualitative interviews. The overarching rationale of utilising this design was to have the qualitative data help explain in further detail the quantitative results, therefore it was vital to connect the quantitative results to the qualitative data collection (Creswell and Creswell, 2018). In this case, the researcher needed qualitative data to explain significant (or non-significant) quantitative results that pointed to differences in self-management between people affected by cancer from rural and urban areas.

Furthermore, this design offered an opportunity to shed light on why the quantitative results occurred and how they might be explained in more detail (Creswell and Plano Clark, 2018).

Figure 3.2 Explanatory Sequential Mixed Methods Design



For the first phase of data collection, quantitative sampling was used, in which a random sample was taken from a cohort of NHS patients that met the study eligibility criteria (see Chapter 4: 4.7.4 Participants). Purposive sampling was then used to select participants for the qualitative data collection, this was primarily to ensure participants from rural-urban areas were equally represented, , as well as, including a wide range of ages, genders and cancer types to explore a range of experiences. Creswell and Creswell (2018) maintain that one of the considerable

challenges is to plan accordingly what quantitative results to follow up on and what participants to collect data from in the second phase. As mentioned earlier, the qualitative data collection should build directly on the quantitative results. The quantitative results highlighted significant (and non-significant) differences between rural and urban participants thus the follow up interviews aimed to collect data from individuals representing both of these categories. The qualitative sample was drawn directly from the initial quantitative sample and participants could self-select to register their interest in taking part in an individual interview.

In terms of data analysis and integration, quantitative and qualitative data were analysed individually and integrated later by connecting the quantitative results to the qualitative data collection. This is considered the point of integration in an explanatory sequential design (Creswell and Creswell, 2018). The quantitative results were used to plan and inform the qualitative follow up accordingly as well as the types of questions that were asked of participants in the in-depth interviews. In line with 'good' qualitative research questions, the researcher made use of open-ended questions and probing to ascertain participants individual experiences of self-management (see Appendix 4: Interview Topic Guide).

In terms of interpretation, the quantitative results were firstly written up in Chapter 5 and the qualitative results follow in Chapter 6. This allowed for the specific research questions outlined earlier to be answered in isolation. However, the explanatory sequential design utilises a third from of interpretation: how the qualitative findings enhance our understanding of the quantitative results (Creswell and Creswell, 2018). Therefore, the researcher presented an in-depth discussion (see Chapter 7) in a standalone chapter on how the qualitative findings in phase two helped to explain the quantitative results from the survey in phase one.

Much like all research designs, mixed methods designs are not without their challenges and Creswell and Plano-Clark (2018) identify a number of these in relation to using the explanatory sequential design. Firstly, the design requires a considerable amount of time and skills in both quantitative and qualitative methods to implement the two phases of data collection (Tariq and Woodman, 2013). Fortunately, the researcher already had experience in conducting quantitative and qualitative studies, as well as, experience in conducting research with people affected by cancer (Nelson et al, 2015; Nelson et al, 2017). However, it was important that the researcher had additional support from an experienced team of academic supervisors who were well versed in quantitative, qualitative and mixed methods research.

Timing was a salient concern in this study as there were delays in obtaining research governance approval to recruit participants to the quantitative phase at one of the recruiting sites. This led to a delay in completing phase one which in turn, meant that qualitative data collection for phase two had to begin before the first phase was complete. Whilst this somewhat compromised the principles of an explanatory sequential design, participants were still purposively sampled for the follow up interviews and delays in data collection should be recognised as a salient concern that researchers are continually faced with when conducting real world research. As the researcher was completing this work for the award of a PhD he was bound by the institutions timescales and so the decision was made to begin data collection for phase two as this involved a considerable amount of travel to collect data. Additionally, there were further delays before a sample of the participants could be contacted for the follow up work which meant that the data collection for phase two was over a longer time frame than initially anticipated

3.8 Conclusion to the Chapter

To conclude, this chapter has provided an overview of the quantitative, qualitative and mixed methods paradigms for conducting research. A brief history of mixed methods and the underpinning philosophy of pragmatism were reported, as well as, the explanatory sequential mixed methods design that was utilised in this study. In addition, the specific research questions that this thesis aimed to answer were outlined at the beginning, as well as, an overview of the philosophical concepts of epistemology and ontology in relation to social research.

In the subsequent chapter a detailed account of the research methods that were used to collect the primary data for this study are reported on. This also includes an overview of how patient and public involvement was incorporated into the study, and the ethical processes and considerations that were pertinent to this research.

CHAPTER FOUR: RESEARCH METHODS

4.1 Introduction to Chapter

This chapter provides an overview of the research methods used to collect the primary data for this study, which used a mixed methods approach incorporating quantitative and qualitative methods. The ability of mixed methods designs to combine the power of numbers, as well as the power of stories (Pluhye and Hong, 2014) adds to their utility in cancer survivorship research (Bender et al, 2016; Klassen et al, 2018; McNulty and Nail, 2015; Scarton et el, 2018) where scholars are giving significant consideration to ways of using both quantitative and qualitative methods to provide richer answers to research questions.

In this study, an explanatory sequential mixed methods design was used where the quantitative questionnaire was followed by a series of qualitative interviews (Curry and Nunez-Smith, 2015). This meant that the quantitative results informed the characteristics of participants to be purposefully selected for the qualitative interviews. The results were analysed separately (Chapter 5 and Chapter 6) and integrated in the discussion (Chapter 7). An advantage of this design was that the qualitative findings served to enhance the understanding of the quantitative results (Creswell and Creswell, 2018).

Firstly, an overview of how people affected by cancer were involved with the research is provided. Subsequently, the ethical approval process is outlined, as well as a discussion on the ethical considerations pertinent to this study. This is followed by the overall study aim and research question. The methods for phase one of data collection, the self-completion postal questionnaire are reported before finally, reporting the methods for phase two of data collection, the qualitative interviews.

4.2 Patient and Public Involvement (PPI) in the Research

The vision that health care and services should be more ‘person’ or ‘patient’ centred so that people have the ability to make choices about their treatment and manage their own health has emerged as a primary approach to healthcare (Coulter, 2011; Delaney, 2018; Munthe et al, 2012). In the UK, ‘Patient and Public Involvement’ (PPI) has become well established within

health and social care policy, helping to empower individuals and communities to play a greater role in shaping health and social care services (DH, 2007; 2008; 2010).

At the same time, PPI has become strongly embedded in wider health research, as well as, promoting involvement specifically with people affected by cancer (Hubbard et al, 2007; 2008) and interest has grown in understanding the difference it makes to research (Brett et al, 2014a). Since 1996, the national advisory group INVOLVE which is funded by the National Institute of Health Research (NIHR) continues to support and enhance public involvement in NHS, public health and social care research and has published a set of guidelines for researchers to consider when involving members of the public in their research (INVOLVE, 2012).

A systematic review (Brett et al, 2014b) reporting the impact of PPI on health and social care research, found that public involvement enhanced the quality and appropriateness of research, notably, the development of user-friendly research materials. Furthermore, Singler et al (2018) explained how involving patients and the public in sharing their experiences of disease as well as the types of research questions that are most important to them can enhance the research process from one that is directed by sponsors and researchers to one that is well informed by the needs of the study population. In addition, the contributions of patients and members of the public can prove valuable in providing alternative views from those of the research team or health and social care professionals (NIHR RDS, 2014).

The INVOLVE (2012) guidelines contend that members of the public should be involved in research as early as possible so they feel part of the research and have a sense of ownership. Therefore, in order to best inform the research as whole, this study aimed to include people affected by cancer from the outset. Firstly, the researcher made contact with senior colleagues at UK charity, Macmillan Cancer Support, to find a suitable public candidate to participate in the Project Steering Group (Chapter 1**:** 1.10 Project Monitoring and Steering Group**)**. This led to a volunteer who had a past diagnosis of cancer and experience as a carer joined the group for the duration of the research. She was actively involved in the research process and was given the opportunity to comment on all aspects of the study from inception and design, through to dissemination of findings.

When designing a questionnaire, Kelley (2003) maintain the importance of considering the overall content; the questionnaire layout, the questions themselves, piloting and the additional

documentation such as the covering letter. The researcher acknowledged the significance of piloting the research materials (cover letter; information sheet; questionnaire; consent form) with people affected by cancer to ensure that they were appropriate and accessible to the study population (INVOLVE, 2012). To do this, the researcher was invited to deliver a short oral presentation introducing the research, its aims and to ask for support with designing research materials at a local cancer support group in Lincoln, UK on the 28th July 2016.

Access was granted to the support group via the public volunteer on the project Steering Group who was the long-term organiser and facilitator of the group. A brief handout was produced (see Appendix 5) and left with members of the support group, all of whom had personal experience of a cancer diagnosis. This gave an overview of the research along with the researcher's contact details to allow for further contact with the researcher. A further three PPI representatives were recruited through the support group. They self-selected to take part by contacting the researcher via the details on the handout. A final representative who had recently been diagnosed and received treatment for cancer, whom the researcher had met at a local research conference, also volunteered their time to review the research materials.

In total, the research materials were piloted with five volunteers who consented for the researcher to have their contact details. Initially, contact was made via telephone or email to reiterate the importance of PPI and what was required of the volunteers. It was made clear that they were helping with designing research materials and not taking part as participants in the research study itself. Shortly after, five research packs were mailed out to each volunteer. Further contact was then made via telephone two weeks later to ascertain their thoughts on the materials. Notes were taken regarding feedback and in some cases the volunteers preferred to email their comments back to the researcher. An example of comments that were reported back via email can be found at Appendix 6. Overall, there was a positive response to the materials and the project as a whole. In their feedback, one volunteer commented *"I think this is going to be really useful research as I hear striking differences in experiences, routines and attitudes between various individuals and groups I meet up with…"* Some of the other suggested changes involved improving the readability of the documents so these were accessible to those with mixed literacy skills, as well as, reinforcing anonymity on the consent form. Suggested changes were adopted where appropriate and used to inform the final materials that were submitted for ethical review.

4.3 Applying for Ethical Approval

Walliman (2016) contends that for research involving human participants, it is likely that ethical approval would need to be granted from a university or other appropriate organisation. Most importantly, this needs to be done prior to approaching potential participants, collecting data, analysing results, writing up and disseminating the findings. In the case of this study, the study population was people affected by cancer, therefore approvals needed to be sought from several different bodies (University of Lincoln; NHS Research Ethics Committee; Health Research Authority; NHS Research and Development and Research and Innovation Departments at the collaborating trusts).

Prior to seeking ethical approval, a range of guidance (Gelling, 2016; HRA, 2017; Smajdor et al, 2009; WHO, 2011) on planning an application and submitting to an ethics committee for review was consulted. The study protocol (see Appendix 7) used a Health Research Authority Protocol Development Tool (HRA, 2016) which supported the researcher to develop a protocol in line with national guidance. In addition, the information sheet (see Appendix 14) and consent form (see Appendix 16) were informed by the Health Research Authority Participant Information Sheet Template (HRA, 2017) and the Consent Form Template (HRA, 2017).

Firstly, an application was made to the University of Lincoln School of Health and Social Care Research Ethics Committee on 10th January 2017. This was reviewed on 25th January 2017. A response was received on 30th January with suggested amendments to the application and supporting documentation. In order to discuss the amendments in more detail, the researcher arranged a Skype conversation with the Chair of the Ethics Committee on 3rd February 2017. A resubmission was made on the 6th February and approval was granted on the 12th February 2017. The approval letter is included at Appendix 8.

This was followed by an application for ethical review to the Health Research Authority (HRA) on 23rd February 2017. This was done online via the Integrated Research Application System (IRAS; Project ID: 204679) and a validation letter was received on 24th February (see Appendix 9). The study was reviewed by the Proportionate Review Sub-Committee of the West of Scotland REC 4 (Ref: 17/WS/0054) on 10th March. The Proportionate Review Service (PRS) provides an accelerated review of research which raises no material ethical issues).

These studies are considered to have minimal risk, burden or intrusion for research participants. A provisional opinion letter was received on 17th March with suggested amendments to the documentation for study participants. A response was submitted to the REC on 10th April 2017 and NHS REC approval was granted on 24th April (see Appendix 10) with HRA approval (see Appendix 11) received on 25th April 2017.

Once HRA approval was received, the next stage was to forward on all REC and HRA approved documentation to both recruiting sites so they could confirm capacity and capability to deliver the study. Firstly, this was sent to United Lincolnshire Hospitals NHS Trust Research and Development Office on 27th April 2017. Authorisation to commence recruitment at this site was granted on 8th May 2017 (see Appendix 12). An application was then made to University Hospitals of Leicester NHS Trust Research and Innovation Department on 14th June 2017 and approval to commence recruitment at this site was issued on 7th August 2017 (see Appendix 13).

4.4 Ethical Considerations in the Research

4.4.1. Harm and/or Distress to Participants

The challenges of conducting research with potentially vulnerable groups (Aldridge, 2012), in particular palliative and terminally ill populations have been well documented (Sivell et al, 2015; Whitehead and Clarke, 2016). Research in this and related health and social care fields is problematic not only because sensitive topics can be discussed but also because researchers might be interacting with participants who are potentially clinically unstable or have complex symptoms and needs (Higginson, 2016).

Whilst those in receipt of palliative care were excluded from this research (see Table 4.1) people affected by cancer who have completed treatment can face significant challenges such as fear of recurrence and psychological needs (Armes et al, 2009) as well as being at risk of ongoing poor physical and mental health outcomes (Burg et al, 2015). Consequently, this makes them a potentially vulnerable group that offer considerable challenges for both researchers and health and social care professionals when documenting and addressing their needs (Rowland and Bellizzi, 2014).

The questions in the questionnaire and in the qualitative interviews were not designed to cause upset to any participant, however, it was acknowledged in the initial Steering Group, as well as PhD supervision meetings (Chapter 1**:** 1.10 Project Monitoring and Steering Group) that some participants may find it distressing to talk about their cancer experience. This was somewhat influenced by the researcher's past experiences conducting qualitative research with people affected by cancer and their carers (Nelson et al, 2015; Nelson et al, 2017) where participants had become tearful when telling their story. At the same time, Wilson et al, (2008) acknowledge that even the completion of a postal questionnaire in quantitative studies could result in psychological distress with some participants when recalling their experiences.

Furthermore, existing work (Sivell et al, 2015) had identified that participant storytelling can be an extremely positive but also emotionally challenging feature of interviewing individuals who are ill, in particular in their home setting.

It was important that participants felt safe and comfortable when taking part in the research (Elmir et al, 2011). Furthermore, the environment should be private and free from interruptions, particularly when discussing sensitive issues (Demsey et al, 2016). Therefore, when conducting the qualitative interviews, in line with Doody and Noonan's (2013) recommendation, the time and location were selected by the participant. The majority of participants were happy to conduct the interviews face-to-face (N=25) and some chose to be interviewed via telephone (N=9). Twenty two participants consented to being interviewed in their own home at a time that was convenient to them. It was important to give participants a choice as it was acknowledged that some might prefer the privacy of talking over the telephone as well as not feeling comfortable inviting a researcher into their home. For those in close proximity to the University, they were also given the opportunity to be interviewed on campus in a private room that was booked in advance by the researcher. Three participants were interviewed on campus and the researcher provided refreshments and reimbursed participants' travel expenses. Two participants requested that their partner accompany them during the interview. This was agreed as it was thought that it would make them feel more comfortable and at ease. The partners were also asked to read and sign a consent form in addition to the participant, although these data were excluded from the analysis reported on in this thesis, as their partner did not meet the study eligibility study.

In order to signpost participants to appropriate services, if necessary, the information sheet and cover letter provided contact details for further cancer support services in Lincolnshire and Leicestershire, as well as, the general Macmillan Cancer Support helpline should anyone have felt the need to talk to someone for further support. For those that became upset during the interviews, Dempsey et al's, (2016) distress protocol was followed where the participant was asked if they would like to take a break and if they wished for the audio recorder to be turned off. Despite the potential for distress, no participants indicated that they needed a break and all (N=34) agreed to continue with no interviews being terminated prematurely.

In addition, prior to conducting the qualitative interviews, a range of Macmillan Cancer Support literature and materials were ordered from the 'Be Macmillan' online service which is available to registered Macmillan Professionals (https://be.macmillan.org.uk/be/default.aspx). These could then be left with any participants should they require it. The extra copies were returned to Macmillan's Information and Support Services to minimise waste. The researcher also left their business card with contact details so the participants could follow up anything they thought appropriate after the interview. Three out of thirty four participants contacted the researcher via email following the interviews with further information about their experiences, this was then added to their individual transcript. There were no instances where participants asked the researcher directly for support with their health or cancer care.

In the initial stages of the study it was decided to send a reminder letter to participants after two weeks if no response was received. Reminder letters are considered a reliable method of maximising response rates in postal surveys (Howell et al, 2003; Schirmer, 2009) when used to politely encourage participants to return their questionnaire. However, one of the PPI volunteers felt that two weeks was sufficient time to respond and suggested that we remove the reminder letter. They stated that this could *"cause upset as not everyone is going to be able to think straight about involvement in research until they can mentally cope with it."* Furthermore, when the study was being reviewed by the West of Scotland NHS REC 4 they too felt that the reminder letter was inappropriate and should be removed. This view is enhanced by the literature (Howell et al, 2003; Robertson et al, 2005) that suggests that multiple reminders are believed to involve harassment or coercion of recipients thereby rendering the requirement that participation should be voluntary as null and void. Consequently, the reminder letter was omitted from the study documentation and not sent to participants who did not return a questionnaire in the first instance.

Finally, prior to conducting the qualitative interviews and making contact with potential participants, the researcher liaised with cancer centre staff at each NHS trust to check patient status. This was to minimise the likelihood of causing distress by contacting friends and families of patients who were recently deceased.

4.4.2. Informed Consent

The provision of information, comprehension of information and voluntary participation are essential to the universal idea of 'informed consent' in ethical research (Marshall, 2006). A significant aspect about participants' choice to take part or not is the quality of the information they receive about the research, enabling them to make a fair assessment of the study so that they can give 'informed consent' (Walliman, 2016).

The initial contact (via post) was from NHS Cancer Centre staff who acted as 'gatekeepers' to the study population. Potential participants were sent a questionnaire (see Appendix 3) that was accompanied with a detailed information sheet (see Appendix 14) and cover letter from the NHS Trust (see Appendix 15). All of these materials were designed to tell the participant more about why they were invited, the purpose of the research and the conditions of taking part. It was made clear on the information sheet and questionnaire that by completing and returning the questionnaire the participant was giving their consent to the conditions outlined in the information sheet.

For the qualitative interviews, written informed consent was taken in person by the lead researcher using a consent form (see Appendix 16). Again, this reiterated agreement with the conditions of the information sheet. One copy was given to the participant to keep and another was kept in a locked metal filing cabinet in the researcher's office at the University of Lincoln, Brayford Campus. For the interviews that were conducted over the telephone, the consent form and information sheet were sent and signed either electronically or via post prior to interview.

4.4.3. Confidentiality

Participants were assigned a unique ID code meaning all quantitative data were anonymised and reported in a way that did not allow individuals to be identified. For the qualitative data, all names were removed from transcripts and participants were assigned a further unique ID code relating to this aspect of the study. Additionally, any names of health and social care

professionals were removed from the transcripts. Where the interview transcripts were externally transcribed a confidentiality agreement was signed and in place (see Appendix 17). Finally, where participants provided their contact details for the follow up interviews these were stored separately from the questionnaire so as they could not be identified.

4.4.4. Data Storage

All physical and digital data were stored safely and securely in the lead researcher's personal office at the University of Lincoln on a password protected PC and in a locked metal filing cabinet. The office and cabinet were locked when not in use. Only the researcher and immediate supervisory team had access to the data.

In line with the University of Lincoln's data management policy (http://www.lincoln.ac.uk/home/abouttheuniversity/governance/universitypolicies/), data will be held for five years following study completion and then destroyed. Paper copies will be shredded and electronic copies deleted.

4.5 Overall Study Aim and Research Question

Prior to reporting on the methods for the quantitative and qualitative data collection it is important to reiterate the intention of the research as a whole. The primary aim was:

To investigate and compare self-management in people affected by cancer following treatment from rural and urban areas.

The research sought to provide a comprehensive answer to the below primary research question:

What are the differences in self-management in people affected by cancer following treatment from rural and urban areas?

4.6 Mixed Methods Research Question

Given the explanatory sequential mixed methods design utilising both quantitative and qualitative methods, a mixed methods research question was included to emphasise how the qualitative data would enhance our understanding of the quantitative findings. The mixed methods research question was:

How does the qualitative interview data on barriers and facilitators to self-management further explain any quantitative differences identified with rural and urban populations?

4.7 Phase One of Data Collection: Methods for the Questionnaire

4.7.1 Aims and Research Question(s)

The quantitative research was undertaken to: (a) identify and compare health promoting behaviours in people affected by cancer from a rural and urban setting; (b) identify and compare patient activation in people affected by cancer from a rural and urban setting; (c) identify and compare cancer-related self-efficacy from a rural and urban setting and (d) to explore the relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy.

The specific research questions were as follows:

- RQ1: What are the differences in health-promoting behaviours in people affected by cancer from rural and urban areas?
- RQ2: What are the differences in patient activation (knowledge, skills and confidence to manage health and health care) in people affected by cancer from rural and urban areas?
- RQ3: What are the differences in cancer-related self-efficacy (belief that one can successfully execute behaviour required to produce expected outcome in relation to consequences of cancer and its treatment) in people affected by cancer from rural and urban areas?
- RQ4: Is there a relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy?

The following null hypotheses (prediction that no relationship or significant difference exists between groups) were derived in relation to each of the specific research questions:

- Null Hypothesis 1: There is no significant difference in health-promoting behaviours in people affected by cancer from rural and urban areas.
- Null Hypothesis 2: There is no significant difference in patient activation (knowledge, skills and confidence to manage health and health care) in people affected by cancer from rural and urban areas.
- Null Hypothesis 3: There is no significant difference in cancer-related self-efficacy (belief that one can successfully execute behaviour required to produce expected outcome in relation to consequences of cancer and its treatment) in people affected by cancer from rural and urban areas.
- Null Hypothesis 4: There is no significant relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy.

4.7.2 Design

This study was cross-sectional in design meaning that data were collected at a single point in time in order to examine patterns of association between variables (Barker et al, 2019). Cross-sectional studies have a number of advantages (Levin, 2006), notably that they are relatively inexpensive and allow the researcher to collect data on multiple variables over a relatively short time period. At the same time, they offer only a snapshot of data at the time of data collection and results may be different if another time frame had been chosen.

The findings and outcomes from cross-sectional studies can be used to inform follow up research such as the qualitative interviews that were conducted in phase two of this study (see 4.8: Phase Two of Data Collection). Through utilising this design it allowed the researcher to collect data in a bid to answer the specific research questions (RQ1-RQ4) and disprove the null hypotheses (NH1-NH4) outlined above.

A self-completion postal questionnaire (see Appendix 3) was used to collect data on demographics, health-promoting behaviours, patient activation, cancer-related self-efficacy and free-text comments regarding further information.

4.7.3 Study Setting

The setting for the study was in the East Midlands of England with the majority of participants resident in the counties of Lincolnshire (55.5%) and Leicestershire (35.2%). The Office for National Statistics (ONS) mid-year 2017 population estimate for the East Midlands as a whole was calculated at 4,771,666 with 751,171 in Lincolnshire and 690,212 in Leicestershire (ONS, 2018).

Lincolnshire is considered a large and sparsely populated county (Lincolnshire Research Observatory, 2018). In comparison to England where seventeen per cent of the total population live in rural areas (Department for Environment, Food & Rural Affairs, 2018), that is in towns of less than 10,000 people, villages, hamlets or isolated dwellings, in Lincolnshire this describes almost half of the total population (48%) and rural areas make up ninety five per cent of the land area.

In Leicestershire, seventy eight per cent of the total population reside in an area classed as an 'urban city and town', thirteen per cent live in areas categorised as 'rural town and fringe' and nine per cent in what is categorised as 'rural village and dispersed' (ONS, 2013).
Consequently, recruiting from two NHS acute trusts in these settings (Lincolnshire and Leicestershire) meant that responses were received from both rural (n=103) and urban (n=120) participants that were equally weighted for comparative statistical analysis.

4.7.4 Participants

Participants were eligible for the study if they: were ≥18, had a confirmed diagnosis of cancer, had undergone cancer treatment in the last five years and were registered on the patient database at United Lincolnshire Hospitals NHS Trust and University Hospitals of Leicester NHS Trust. Participants were excluded from the study if they: were <18, had evidence of cancer recurrence/metastatic spread, had started active oncology treatment within the last twelve months or were being treated for best supportive/palliative care. In order to be as inclusive as possible, and to account for differences in the patient pathway, the population was not refined to people with any specific cancer type. Full inclusion and exclusion criteria can be found in Table 4.1.

Compared with cancer in adults, cancer in teenagers and children is relatively rare and the distinctive care needs of younger populations (O'Hara et al, 2018) meant that the researcher,

with guidance from the Steering Group, decided to only include those who were over seventeen years of age. Participants had to have undergone treatment for cancer in the last five years as the study was interested in how participants self-manage the long-term consequences of a cancer diagnosis and treatment. Those who were currently undergoing active oncology treatment within the last twelve months were excluded, as again, the study wanted to examine longer-term effects and recovery, as opposed to the more immediate side effects from treatments such as chemotherapy and radiotherapy.

Table 4.1 Participant Eligibility Criteria

Inclusion	***Exclusion***
Eighteen years of age or older	Under eighteen years of age
Confirmed diagnosis of cancer and registered on the cancer patient database at the largest acute NHS Trusts at the two study sights	Evidence of cancer recurrence and/or metastatic spread
Undergone cancer treatment within the last five years.	Started active oncology treatment within the last twelve months.
Participants must be willing and able to provide informed consent	Currently being treated for best supportive or palliative care
Participants must have a good command of the English language (for phase one and two) and an adequate level of hearing (for phase two; qualitative interviews)	Participants who do not have an adequate level of spoken or written English.

4.7.5 Sample Size Calculation

The researcher worked with an experienced statistician at the University of Lincoln to calculate the sample size and a letter of support (see Appendix 18) was provided to the Proportionate Review Sub-Committee of the West of Scotland REC 4. The sample size was determined on the basis of a power calculation using the statistical software package *Minitab* (Version 17). The ability of a test to find an effect is known as its statistical power. The power of a test is the probability that it will find an effect assuming that one exists in the population (Field, 2018). The calculation was performed for a two sample (rural and urban) *t*-test for each of the three quantitative outcome measures in the questionnaire (HPLP-II; PAM-13; CSSES). The largest total was taken as the required sample size. The final calculation allowed for a 20 per cent difference between scores, assumed a statistical significance level of 0.05, and a test with 95 per cent power giving a required sample size of 417. In line with similar research (Shneerson et al, 2015a; 2015b) on self-management in people affected by cancer in the West

Midlands of England, that also used a self-completion postal questionnaire, the sample size was doubled, as it was anticipated that 50 per cent of participants would respond. Therefore, 834 participants that met the above eligibility criteria were identified and sent a research pack.

4.7.6 Recruitment to the Study

Access to the sample population was sought through Cancer Centre staff at the collaborating NHS trusts who acted as gatekeepers to the study population. The initial stages of the research involved frequent face-to-face meetings and correspondence via email and telephone with senior staff from each Cancer Centre to ensure that they could recruit according to the eligibility criteria and that they were content with the methods of recruitment.

The study purpose, along with the inclusion and exclusion criteria was explained to the Macmillan Lead Cancer Nurse and Cancer Centre Manager at each site who agreed to identity and contact potential participants using their cancer patient database (InfoFlex; UHL and Somerset; ULHT) on behalf of the research team. The researcher had no access to identifiable patient data.

The researcher printed and assembled 834 research packs at the University of Lincoln, Brayford Campus. The research packs included the following documents:

- NHS Trust Cover Letter from Macmillan Lead Cancer Nurse (see Appendix 15).
- Participant Information Sheet, Version 2.1; 20/03/17 (see Appendix 14).
- Questionnaire, Version 2.0; 16/02/17 (see Appendix 3).
- Further Contact Slip (see Appendix 19).
- Freepost Return Envelope with University of Lincoln address

417 research packs were boxed and sent to United Lincolnshire Hospitals NHS Trust Cancer Centre via the University's outgoing post on 24th May 2017. Together with the research packs, the researcher sent a letter (see Appendix 20) to the Cancer Centre Manager and Macmillan Lead Cancer Nurse, in the post and electronically, that reiterated the eligibility criteria and process of recruitment. The Macmillan Lead Cancer Nurse at that site confirmed receipt on the 5th June 2017. An Information Analyst at the Cancer Centre then identified potential participants for the research using their patient database. Of all the patients who met the eligibility criteria, a random list of 417 were selected and the research packs were posted the

week commencing 19th June 2017. The database did not contain any personal information such as name or address. Therefore, the patient's NHS number was cross-checked with the Patient Administration System (PAS) to obtain name and address. Cancer Centre Staff had to input the address of the participant on the front of the envelope and a unique ID code on the second page of the questionnaire. Using the unique ID codes, staff maintained a record of all those who were sent a research pack in a database file. This was later shared with the researcher to allow access to the patient's medical information where appropriate.

The above process was replicated at University Hospitals of Leicester NHS Trust with a further 417 research packs. The research packs were hand delivered by the researcher on the 4th August 2017 to the Cancer Centre at Leicester General Hospital. Finally, confirmation was received via email that these were posted to potential participants that met the eligibility criteria on 26th September 2017.

It was made clear on the participant information sheet that completing and returning the questionnaire implied informed consent and granted access to their medical records. In the event of participants having any queries regarding the study, the researcher's contact details were provided.

Surveys were returned to the researcher via a freepost envelope included in the research pack. Questionnaires were coded upon receipt and hard copies stored in a locked metal filing cabinet in the researcher's personal office at the University of Lincoln, Brayford campus.

4.7.7 Questionnaire Design

The questionnaire comprised of five sections which are detailed below.

4.7.7.1 Section One: Demographic Variables

In section one, the questionnaire collected data on age, gender, ethnicity, living arrangements, marital status, employment status, qualifications, annual household income, post code (to define rural-urban residency) and self-reported health status. For self-reported health status, participants were asked the question 'How is your health in general?' and they could rate their health as 'Very Good', 'Good', 'Fair', 'Poor' or 'Very Poor'. This was in line with existing research exploring rural-urban differences in health-behaviours and health status with

American cancer populations that also asked respondents to self-report their health status (Weaver et al, 2012; 2013).

4.7.7.1.1. Rural-Urban Residence

Rural-urban residence was defined based on the UK Office for National Statistics (ONS) RUC2011 Rural Urban Classifications (Bibby and Brindley, 2013). Respondents were asked for their postcode within section one of the questionnaire and the online ONS postcode directory look-up tool (http://onsdigital.github.io/postcode-lookup/) was used to assign them to one of four urban or six rural categories (see Table 4.2). Following this, and based on the below, respondents were also assigned to a dichotomous variable categorised as rural or urban to allow for comparison between the two groups. The classification is an Official Statistic and according to the Department for Environment, Food and Rural Affairs (2017) should be utilised for statistical analysis. Similarly, the use of official statistics to define rural-urban residence is also in line with existing cancer research by Burris and Andrykowski (2010) and Weaver et al (2012; 2013).

Table 4.2 UK Office for National Statistics RUC2011 Rural Urban Classifications

	RUC2011 Classification
Urban	A1: Urban Major Conurbation
	B1: Urban Minor Conurbation
	C1: Urban City and Town
	C2: Urban City and Town in a Sparse Setting
Rural	D1: Rural Town and Fringe
	D2: Rural Town and Fringe in a Sparse Setting
	E1: Rural Village
	E2: Rural Village in a Sparse Setting
	F1: Rural Hamlets and Isolated Dwellings
	F2: Rural Hamlets and Isolated Dwellings in a Sparse Setting

4.7.7.2 Section Two: Health Promotion Lifestyle Profile II (HPLP-II)

In section two, the HPLP-II (Walker et al, 1995) was used to measure the health-promoting behaviours. Despite being developed in the late 1980s and updated in the mid-1990s the scale is still frequently used in range of different health studies with diverse populations (Kurnat-Thoma et al, 2017; Thacker et al, 2016) including people affected by cancer (Gates et al, 2015). It consists of fifty-two items and is categorised into six health-promoting subscales as outlined in Table 4.3.

The questionnaire asked respondents to indicate how often they practice specific health-promoting behaviours or well-being habits on a fixed four point Likert scale where "never" was coded as 1, "sometimes" as 2, "often" as 3, and "routinely" coded as 4. For example, how often do they "Follow a planned exercise programme", "Take some time for relaxation", "Eat 3-5 servings of vegetables a day", "Use specific methods to control stress", "Attend educational programmes on personal health care." A mean score is calculated for all 52 items giving the overall health-promoting lifestyle, as well as, for each of the six subscales.

Table 4.3 Internal Consistency of HPLP-II Subscales

HPLP II Subscale	**Items**	α	***N*=**
Health Responsibility	3, 9, 15, 21, 27, 33, 39, 45, 51	0.77	9
Spiritual Growth	6, 12, 18, 24, 30, 36, 42, 48, 52	0.85	9
Physical Activity	4, 10, 16, 22, 28, 34, 40, 46	0.84	8
Interpersonal Relations	1, 7, 13, 19, 25, 31, 37, 43, 49	0.83	9
Nutrition	2, 8, 14, 20, 26, 32, 38, 44, 50	0.77	9
Stress Management	5, 11, 17, 23, 29, 35, 41, 47	0.72	8
Overall Health Promoting Lifestyle Profile	1-52	0.94	52

α refers to Cronbach's alpha measure for internal consistency

Walker et al (1995) reported high reliability with a Cronbach's alpha (α) of 0.92 for the total HPLP-II and α ranging from 0.70 to 0.90 for the six subscales. In this study, reliability for the total HPLP-II was also high with α of 0.94, and α ranged from 0.72 to 0.88 in the six subscales indicating good reliability (see Table 4.3).

4.7.7.3 Section Three: Patient Activation Measure (PAM-13)

Section three collected data on patient activation using the short form of the Patient Activation Measure (PAM-13) developed by Hibbard et al (2005). The researcher obtained a licence from the American company Insignia Health to use the scale and permission was granted on 19/05/16. Patient activation is defined as the knowledge, skills and confidence an individual has to manage their health and health care (Hibbard et al, 2004). Respondents were asked to indicate how much they agree or disagree with a set of 13 statements about their health where "disagree strongly" was coded as 1, "disagree" as 2, "agree" as 3, "agree strongly" as 4, and "not applicable" coded as 5. The measure is scored on a 0-100 scale. Higher scores indicating higher levels of patient activation.

In addition to an overall activation score participants are assigned to one of the four levels of patient activation: (1) participants tend to be passive and feel overwhelmed by managing their own health; (2) participants may lack the knowledge and confidence to manage their health; (3) participants appear to be taking action but may still lack the confidence and skill to support their behaviours and (4) participants have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors (Hibbard and Gilburt, 2014). These levels represent progression from a passive care recipient (level one) to individuals who are more proactive in self-managing their health and health care (level four) (Hibbard et al, 2004; 2005).

Example questions include "I am the person who is responsible for taking care of my health", "I understand my health problems and what causes them", "I am confident I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress."
Recent research (O'Malley et al, 2018) utilising the PAM-13 with people affected by breast and prostate cancer reported α of 0.89. In this study, α for the PAM-13 was 0.85 also indicating good internal consistency.

4.7.7.4 Section Four: Cancer-Related Self-Efficacy

Section four collected data on cancer-related self-efficacy. The 11 item Cancer Survivors Self-Efficacy Scale (Foster et al, 2013) was used. The scale was developed by the Macmillan Survivorship Research Group at the University of Southampton and the researcher asked for permission to use the scale on 05/10/16. Permission was granted on 07/10/16.

The scale comprised of the Self-Efficacy for Managing Chronic Disease Six-Item Scale (Lorig et al, 2001) with an additional five items that directly refer to self-managing the effects of cancer and its treatment. Participants rated their confidence to perform self-management behaviours (1=not at all confident to 10=totally confident). For example, "How confident are you that you can access information about your cancer and any effects of the diagnosis and treatment?" or "How confident are you to contact your doctor about problems caused by your cancer/treatment?" A mean score was calculated for the 11 item scale as a whole and a higher score was indicative of high self-efficacy.

In Foster et al's (2015) research on confidence to self-manage with people affected by cancer who were one year following primary treatment, α was reported as 0.92 indicating high reliability. In this study, α was also high with a value of 0.94 (11 item) indicating high internal consistency.

4.7.7.5 Section Five: Further Information

Finally, section five asked participants for any further information that they felt was relevant to how they manage their health and health care. O'Cathain and Thomas (2004) have encouraged researchers to use general open-ended questions at the end of questionnaires in order to optimise the quality of data and subsequent analysis. At the same time, Garcia et al (2004) maintain that free-text comments are no substitute for properly designed research, however, they do emphasise their utility in understanding and illustrating participants' survey responses. Notably, free-text responses have been utilised in national cancer patient experience surveys in England (Wiseman et al, 2015), Scotland (Cunningham and Wells, 2017) and Wales (Bracher et al, 2016). For Wiseman et al (2015), the use of free-text responses in surveys has the potential to highlight aspects of the cancer experience that closed questions might not reveal.

In this case, the data were collected using an open-ended question that encouraged respondents to answer however they wished. Respondents were asked the following*: 'Thinking about how you manage your health and health care, if there is anything else you would like to tell us about your experience, please write in the box below.'* The free text response was intentionally placed at the end of the questionnaire to encourage respondents to reflect on, and add to, their responses to the previous sections.

On the final page, the questionnaire also allowed respondents to opt in to receiving a summary of the study findings by ticking a box. 159 (70%) participants requested a summary of the results.

4.7.8 Statistical Analyses

Data were analysed using SPSS software (Version 22). Firstly, descriptive statistics were used to characterise the data on demographics, health-behaviours, patient activation and cancer-related self-efficacy. Frequencies, percentages, mean values, the range and standard deviations (SD) were reported. The SD refers to the average variability or spread of a set of data in the same units of measurement as the original data (Field, 2018) and is reported alongside the mean value. A low SD indicates that most of the responses for that particular item are close to the mean and a high SD is representative of greater spread or variance in the data.

Pearson's *r* and Spearman's Rho were used to assess the strength and relationship between demographic and study variables, as well as, between the three outcome measures (HPLP-II; PAM; CSSES). The direction of the relationship is indicated by the *r* value. Positive correlations (r=0 to+1) emerge when the two variables move in the same direction and negative correlations (r= -1 to 0) emerge when the variables move in different directions (Knapp, 2017). The strength of the relationship is indicated by the numeric value of *r* with the closer to 0 being representative of no correlation or a weak relationship (Field, 2018).

The Independent Samples *t* test (Bors, 2018) was used to assess whether there was a statistically significant difference between rural and urban respondents in relation to the mean values on each of the outcome measures (HPLP-II; PAM; CSSES). Full SPSS output for the *t* tests on all outcomes can be found at Appendix 21. Results were considered statistically significant if p<0.01. The *t* Test is frequently referred to as a parametric test that assumes that the sample data are normally distributed (data are symmetrical about the mean). Where data are not normally distributed researchers are frequently encouraged, albeit often incorrectly according to Lumley et el (2002) to use their non-parametric alternatives (such as the Mann Whitney *U* Test). Nonetheless, for Skovlund and Fenstad (2001), the Independent Samples *t* test tends to be robust to deviations from normality, in particular when the sample size increases. Furthermore, according to Fagerland and Sandvik (2009) when the sample size is two hundred or more, the *t* test is robust even when working with heavily skewed distributions.

For Fagerland (2012), non-parametric tests are best utilised when working with small sample sizes and in studies with larger samples (N=≥200), such as this research (N=227), the *t* test and corresponding confidence intervals (range of values for the estimated population that contain the true mean) can and should be utilised regardless of whether the outcome variables were normally distributed (Fagerland, 2012). For one of the outcome measures, the fifty two item HPLP-II, the sample size was <200 (N=160) and so the data were charted in SPSS as a histogram with a normal curve and the distribution was not considered to be heavily skewed (see Appendix 22). Furthermore, to reinforce that the HPLP-II data were from a normal distribution, the Shapiro-Wilk Test (see Appendix 22) was ran and generated a *p* value of .778 (rural) and .445 (urban) which was $p>0.05$ suggesting that the alternative hypothesis (data were not normally distributed) could be rejected and the data were normally distributed. Therefore, it could be concluded that the Independent Samples *t* Test was an appropriate test to compare between rural and urban on the HPLP-II despite the sample size being less than two hundred.

The homogeneity of variance was also checked on all outcome measures which pertains to checking that the variances of the two groups (rural, urban) that are being compared are similar to each other (Knapp, 2017). In SPSS, Levene's Test for Equality of Variance (see Appendix 21) was ran and where this generated a *p* value greater than .05, this indicated that there was no statistically significant difference between the variance of the rural group compared to the urban group. In the few instances where this was significant, the non-parametric Mann Whitney *U* test was utilised to test for significance between groups (Items 2, 3, 10 on the CSSES).

Next, to identify the effect of any potentially confounding variables on rural-urban residence, Pearson's *r* and Pearson's chi-square ($\chi 2$) test were run. Multivariate analysis was then conducted whilst controlling (reducing the effect of confounding variables) for other independent confounding variables. This was to ascertain the effect of rural-urban residence on the three outcome variables (HPLP-II; PAM-13; CSSES) whilst adjusting for other variables that had a significant association with residency. Results were considered statistically significant if $p<0.01$.

4.7.9 Missing Data

It is not uncommon for questionnaire data to be incomplete meaning that some responses are missing and Bors (2018) suggests several reasons for this. Firstly, participants might simply

refuse to answer a question. Additionally, this missing data might be caused by respondents refusing to provide personal information such as income, education or religious affiliation. In some cases, the participant may accidentally overlook a question and not realise that they have not answered it. Similarly, with longer questionnaires respondents can accidentally skip over items. An individual might be unsure of their response and intend to return to a question later but forget to do so. Finally, certain questions may not be applicable to particular respondents.

In this study, the level of missing data was relatively low with the exception of the HPLP-II. This could potentially have been down to the length of the scale at 52 questions and that some participants felt that some of the questions were not relevant or appropriate to their situation. This was highlighted through the qualitative responses at the end of the questionnaire where several participants reported this. For example, one participant (ID044) said "1. Due to vascular issues; mobility is impaired; thus questions re exercise are not relevant! 2. Due to an Ileostomy following surgery for cancer responses to questions re diet are not relevant!" Furthermore, another respondent (ID073) said "I have put N/A to several of the dietary choice questions as I am artificially fed via RIG tube." Therefore, data for the HPLP-II was thought to be mostly 'Missing Not At Random' (MNAR) and so did not warrant any data substitution or imputation, as the responses were likely missing due to the participant's own individual circumstances with some of the health-behaviours not being possible to engage with given their health needs.

For the PAM-13, in line with the instructions that were sent to the researcher via Insignia Health Ltd., the respondent needed to answer at least ten of the thirteen questions to be given an activation score. Therefore, any participants with less than ten responses were excluded from the analysis. For the CSSES the advice from Lorig et al (2001) who designed the Self-Efficacy for Managing Chronic Disease Six-Item Scale was followed which meant that if two or more items were missing then the scale was not scored.

The approach taken to missing data was to omit those cases with the missing data and analyse the remaining data when computing mean scores for the outcome variables. According to Kang (2013), this is the most common approach to handling missing data and is known as the complete case (or available case) analysis. As mentioned previously, the percentages of missing data were relatively low for all outcome variables (4.8%-10.1% of total sample), with the exception of the HPLP-II 52 Item, therefore, it was not felt that it was needed to manipulate

the data using techniques such as mean substitution or regression imputation (Kang, 2013). When coding the questionnaires, if a respondent did not answer a question then this was coded in SPSS as '998' for missing. The percentages of missing data for each subscale are reported on in Table 4.4.

Table 4.4 Missing Data: HPLP II; PAM-13; CSSES

Scale	Missing *N*	% Total Sample	Analysis *N*
HPLP II 52 Item	67	29.5	160
HPLP II Health Responsibility	22	9.7	205
HPLP II Physical Activity	16	7.0	211
HPLP II Nutrition	11	4.8	216
HPLP II Spiritual Growth	23	10.1	204
HPLP II Interpersonal Relations	21	9.2	206
HPLP II Stress Management	17	7.5	210
PAM-13 Item	12	5.3	215
CSSES	19	8.4	208

Note: Total n=227

Finally, in order to ensure the data were entered accurately, a random sample of ten per cent of questionnaires (N=27) were checked by a Research Assistant at the University of Lincoln who was independent from the study.

4.7.10 Free-Text Analyses

The participants' free text data was analysed using thematic analysis (Braun and Clarke, 2006) to systematically organise and review data. Thematic analysis was most suitable for the analysis as the focus was on what was said, rather than how it was said, (Reissman, 2005). The intention was to seek patterns of meaning across the dataset of people living with and beyond cancer diagnosis (Creswell and Creswell, 2018; Braun and Clarke 2006; Miles et al, 2014). Thematic analysis also afforded the opportunity of identifying what was different to the way the topic is written about, and of making sense of those differences (Miles et al, 2014).

Thematic analysis can be applied in a variety of ways, either focusing on a theoretical approach or an inductive approach. The former, deductive method emphasises the underpinning theoretical ideas drawn from existing literature in the field (Braun and Clarke 2006). The latter,

inductive method, is influenced entirely by meaning in the dataset itself. In this study two of the free text analysts were 'blind' to the theoretical aspects of self- management, while the third was more familiar thereby adding rigour for credibility and authenticity to the analysis (Barker. and Linsley, 2019). Therefore, the process of analysis in this aspect of the study provided an interesting co-study on the inductive and deductive methods used in thematic analysis.

Much like the qualitative interviews, the phases of data analysis followed the framework proposed by Braun and Clarke (2006) and are outlined later in this chapter.

4.8 Phase Two of Data Collection: Methods for the Interviews

4.8.1 Aims and Research Question(s)

Phase two of the research involved a series of qualitative interviews (n=34*)* that aimed to identify, and compare, the barriers and facilitators to self-management in people living with and beyond cancer in rural and urban settings.

The specific research questions for this phase of the research were:

- RQ5: What are the barriers and facilitators to self-management in people affected by cancer?
- RQ6: Do the barriers and facilitators to self-management differ in rural and urban areas?

4.8.2 Recruitment of Participants for the Qualitative Interviews

The self-completion questionnaire gave participants the opportunity to register their interest in the qualitative interviews by returning a further contact slip (see Appendix 19) with their contact details (name, phone number and email address). This was found at the end of the questionnaire. These were stored securely and separately from the questionnaire response so as no participant could be identified. Across both trusts, a total of 112 further contact slips indicating that the participant would be happy to be contacted about the possibility of taking part in an interview were returned to the researcher with a completed questionnaire.

Given a number of months had passed since participants were first screened against the eligibility criteria, the researcher had to liaise with staff at both Cancer Centres to ensure that

participants still met the initial eligibility criteria (see Table 4.1). Furthermore, this minimised the risk of causing distress to friends or families by contacting participants who were now deceased, as well as, those who were now in receipt of palliative or end of life care.

4.8.3 Qualitative Data Collection

A total of 34 participants took part in an in-depth qualitative interview between 31st October 2017 and 4th June 2018. Interviews were conducted face-to-face (N=25) and via telephone (N=9). During the initial contact (telephone or email) with potential participants, both options were made available, in order to best accommodate participants who had a busy schedule or perhaps were not comfortable with inviting a researcher into their home. Those who resided in close proximity to the University of Lincoln, were given the option of attending an interview on campus in a private room that was booked in advance. Travel expenses were reimbursed for the participants who came to the University (N=3). The majority of participants (N=22) were interviewed in their home at a range of locations across the East Midlands of England. When conducting the face-to-face interviews in participants homes, the researcher adhered to the University of Lincoln's lone working policy (see Appendix 23). Interviews ranged from approximately 30 to 100 minutes and were digitally recorded. Prior to interview, the researcher went through the original information sheet (see Appendix 14) and gave the participant the opportunity to ask any questions. Next, the participant was asked to read and sign a consent form (see Appendix 16). For those who took part via telephone, the information sheet and consent form were sent either by post or electronically in advance of the interview. In some cases, the interviewee requested that their partner be included in the discussion, for those interviews, they were also asked to read and sign a consent form.

Whilst the interviews allowed for open-discussion around the individual's experiences of cancer and self-management, the topic guide was used to guide the structure of the interview (see Appendix 4). It was structured into four sections: (1) background; (2) self-management; (3) location and (4) close. Section one asked questions in relation to the participant's background information and their experiences of cancer (diagnosis, treatment, and follow-up care). Section two asked questions about self-management, what it means to them, what self-management practices they engage with, as well as, what prevents or enables them from managing their health. In section three, participants were asked questions about where they live and the impact this has on how they manage their health and health care. Finally, section four gave participants the opportunity to add anything they felt was important about their

cancer experience. Throughout the discussion, the researcher used follow-up questions and probed where appropriate in order to obtain as detailed a narrative as possible. For an example of a completed transcript, please see Appendix 24.

4.8.4 Qualitative Data Analysis

Qualitative research frequently involves some form of transcription (Oliver et al, 2005) and for Davidson (2009), the use of external transcribers is integral to the production of data in many qualitative studies. In this research, all the interviews (N=34) were transcribed verbatim (15 by the lead researcher, 14 by an external transcription service and 5 by a Research Assistant at the University of Lincoln) and imported into the Computer Aided Qualitative Data Analysis Software (CAQDAS) NVivo (Ver. 11).

Qualitative data were analysed using Braun and Clarke's (2006) approach to thematic analysis and the individual steps in this framework are reported on below. It is a method for identifying, analysing and reporting patterns in qualitative data. This method was chosen as it allows for an accessible, systematic and rigorous approach to coding and theme development (Howitt, 2010). The method has been widely used across a range of disciplines in the social, behavioural and health sciences, including extensively in cancer survivorship research (Barber, 2013; Beeken et al, 2016; Dunne et al, 2018; Fenlon et al, 2013).

The researcher and two members of the supervisory team with extensive experience in qualitative research all read transcripts and generated initial codes. The researchers independently coded the transcripts in NVivo and met regularly to discuss the codes and reconcile differences until agreement was reached. The six stages of thematic analysis are outlined below:

4.8.4.1 Stage One: Familiarisation

The researcher conducted all of the interviews and transcribed fifteen of them so there was a substantial level of familiarity with the content of the interviews prior to analysis. However, when conducting thematic analysis it was important that the researcher became well versed in their content before the coding process began. Therefore, the researcher read and reread the transcripts several times to become immersed and familiar with the data. An example of a completed interview transcript can be found at Appendix 24. At this stage, notes and early impressions of the data were recorded in a notebook. It was important for the researcher to be

familiar with all of the transcripts (Maguire and Delahunt, 2017) before moving on to coding the dataset in stage two.

4.8.4.2 Stage Two: Coding

The next stage involved generating succinct labels or codes that identified important features of the dataset that were appropriate for answering the research question (Braun and Clarke, 2006). It involved going through the whole dataset in a systematic manner and collating codes through reducing large quantities of data into smaller chunks of meaning (Maguire and Delahunt, 2017). This was the first step in the process of identifying patterns in the data because it grouped together similar components of data. The coding process was concerned with addressing a specific research question (RQ 5-6) and so the researcher worked through each transcript coding text that seemed to be relevant to, or directly related to addressing the research question. Open-coding was used which meant that rather than using pre-set codes, codes were developed and modified as the researcher moved through the coding process. Transcripts were independently coded by the researcher and two members of the supervisory team. In order to do this all of the transcripts were imported into the qualitative software package NVivo. See Appendix 25 for an example of a coded interview transcript.

4.8.4.3 Stage Three: 'Searching' for Themes

The third stage was concerned with examining the codes and identifying significant broader patterns of meaning that could be potential themes. Clarke et al (2015) maintain that whilst the term 'searching' is used to describe this stage, the researcher is not looking for something that already exists; instead, they are concerned with mapping the data in a plausible and coherent manner. In this case, the researcher collated relevant data to each potential theme so that they could work with the data and review the viability of each potential theme.

4.8.4.4 Stage Four: Reviewing Themes

The next stage involved pausing the process of theme generation and reviewing the themes that had been generated thus far. This was to ensure that potential themes were a good representation of the data that had been coded as well as the dataset as whole.

4.8.4.5 Stage Five: Defining and Naming Themes

The penultimate stage, involved drafting up a summary of each theme and deciding on a theme name ensuring the conceptual clarity of each theme and thus, providing a road map for the subsequent write up (Braun and Clarke, 2006). This involved developing a detailed analysis of each theme, defining the scope and focus as well as the story behind it. The theme names were decided on by the researcher and discussed in collaboration with the supervisory team.

4.8.4.6 Stage Six: Writing the Results

The final stage involved combining the analytic narrative and data extracts, as well as, contextualising the findings in relation to the existing literature (Braun and Clarke, 2006). In this case, the final findings from the qualitative interviews were written up in the form of an individual thesis chapter (see Chapter 6). The findings were then interpreted in relation to the extant literature in the discussion section of this thesis (see Chapter 7).

4.9 Reporting the Qualitative Results

It should be noted that when reporting the qualitative results in Chapter 6 the use of numbers was avoided. For example, 'twenty out of thirty four participants reported that community and peer support influenced their recovery following treatment.' When conducting qualitative research, the data generated from each person can be rather different given that interviews are a fluid, flexible and interactive data collection tool (Clarke et al, 2015) and it is not always the case that every participant discusses exactly the same issues or even in the same context. So returning to the above example, we cannot be sure that the remaining fourteen participants thought that community and peer support did not influence their recovery, or even felt the opposite, they may have just not discussed this during the interview. Therefore, we have no way of interpreting what is not reported in the data, and consequently, for Braun and Clarke (2013) 'qualitative research is about meaning, not numbers', thus making the numerical reporting of qualitative findings deceptive and disingenuous. Furthermore, this is in alignment with the Australian health researcher Priscilla Pyett (2003, p. 1174) who maintains that 'counting responses misses the point of qualitative research' as frequency does not determine value. Finally, interpretivist philosophy would posit that whether something is insightful or important for answering the research question is not necessarily determined by whether large numbers of people said it.

4.10 Conclusion to Chapter

This chapter has reported on the research methods that were utilised to collect primary data for this doctoral thesis on self-management in people affected by cancer from rural and urban settings. In addition to the methods of data collection, an overview of how PPI was integrated into the study design was provided, as well as, the key ethical considerations that were pertinent to this research. The study used an explanatory sequential mixed methods design incorporating firstly, quantitative methods of inquiry using a self-completion postal questionnaire (N=227), and secondly, qualitative data collection through a series of in-depth interviews (N=34). The context to these different research paradigms and a rationale for their use was provided in the methodology section (see Chapter 4) that preceded this chapter. The subsequent chapters that follow report on the research findings from both the questionnaire (see Chapter 5) and the interviews (see Chapter 6).

CHAPTER FIVE: QUESTIONNAIRE RESULTS

5. 1 Introduction to Chapter

This chapter presents the results from the self-completion postal questionnaire that collected demographic data, data on health-promoting behaviours, patient activation, cancer related self-efficacy and free-text responses with further information relating to self-management from people affected by cancer.

The results in this chapter directly relate to the first four aims of the research: (a) to identify and compare health-promoting behaviours in people affected by cancer from rural and urban areas; (b) to identify and compare patient activation in people affected by cancer from rural and urban areas; (c) to identify and compare cancer related self-efficacy in people affected by cancer from rural and urban areas and (d) to explore the relationship between health-promoting behaviours, patient activation and cancer related self-efficacy.

In order to offer insight into the characteristics and responses of the sample as a whole, descriptive statistics are provided throughout this chapter. Independent Samples *t* tests have been conducted to compare mean scores where appropriate, as well as, bivariate analyses to examine the relationships between outcome variables and any potential covariates. A further bivariate analyses between the three primary outcome measures (HPLP-II; PAM-13; CSSES) was conducted and is reported on. Additionally, the thematic analysis of the free-text responses at the end of the questionnaire are presented. Finally, the results from the Independent Samples *t* Tests that compare mean scores between rural and urban participants are presented, as well as, multivariate analysis on all three outcome measures whilst controlling for confounding variables.

The specific research questions answered in this chapter were as follows:

- Research Question 1: What are the differences in health-promoting behaviours in people affected by cancer from rural and urban areas?
- Research Question 2: What are the differences in patient activation (knowledge, skills and confidence to manage health and health care) in people affected by cancer from rural and urban areas?

- Research Question 3: What are the differences in cancer-related self-efficacy (belief that one can successfully execute behaviour required to produce expected outcome in relation to consequences of cancer and its treatment) in people affected by cancer from rural and urban areas?
- Research Question 4: Is there a relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy?

The following null hypotheses were derived in relation to each of the specific research questions:

- Null Hypothesis 1: There is no significant difference in health-promoting behaviours in people affected by cancer from rural and urban areas.
- Null Hypothesis 2: There is no significant difference in patient activation in people affected by cancer from rural and urban areas.
- Null Hypothesis 3: There is no significant difference in cancer-related self-efficacy in people affected by cancer from rural and urban areas.
- Null Hypothesis 4: There is no significant relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy.

Null hypotheses 1, 3, and 4 were disproved based on the results of the questionnaire findings that found significant differences ($p<0.01$) between rural and urban respondents on the quantitative outcome measures (HPLP-II; CSSES) as well as a relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy. The second null hypothesis was accepted as there was no significant difference in patient activation in people affected by cancer from rural and urban areas at $p<0.01$.

5. 2 Characteristics of Participants

A total of 227 participants completed and returned a questionnaire giving a response rate of 27 per cent. The mean age of respondents was 66.86 years. ± 11.22 (range 26-90). Fifty two per cent (N=119) were female and forty eight per cent (N=108) were male. In terms of ethnicity and religion, the overwhelming majority of the sample were white British (N=220) and seventy nine per cent (N=179) identified as Christian. Seventeen per cent (N=39) reported that they

live alone. Most respondents (N=169) reported being married. Regarding employment status, the majority of participants were retired (N=148) and eighteen per cent (N=40) reported having obtained a degree or higher degree qualification. Thirty two per cent (N=73) of respondents had an annual household income of £25-49,999. Forty four per cent (N=99) of participants self-reported their health as good. Fifty three per cent (N=120) of the sample resided in urban areas and forty five per cent (N=103) in rural areas. In terms of the county participants were resident in, fifty six per cent (N=126) resided in Lincolnshire and thirty five per cent (N=80) in Leicestershire. Finally, the most common primary cancer type was breast (N=73) followed by urological (N=53) and upper and lower gastrointestinal (N=41). Full demographic data of participants are presented in Table 5.1.

Table 5.1 Demographic Characteristics of Questionnaire Participants

	All respondents *N*=227	***n* (%)***
Age	25-34	1 (0.4)
	35-44	6 (2.6)
	45-54	27 (11.9)
	55-64	50 (22.0)
	65-74	90 (39.6)
	Over 75	52 (22.9)
Gender	Female	119 (52.4)
	Male	108 (47.6)
	Other gender identity	0 (0)
Ethnicity	White British	220 (96.9)
	Indian	5 (2.2)
	African	1 (0.5)
	Caribbean	1 (0.5)
Religion	Christian	179 (78.9)
	No Religion	37 (16.3)
	Hindu	3 (1.3)
	Muslim	1 (0.4)
	Sikh	1 (0.4)
	Any other religion	1 (0.4)
Living arrangements	Partner/Spouse/Family/Friends	185 (81.5)
	Alone	39 (17.2)
	Nursing home, hospital, long-term care home	1 (0.4)
Marital status	Married	169 (74.4)
	Living with partner	6 (2.6)
	Widowed	23 (10.1)
	Single	10 (4.4)
	Divorced/Separated	18 (7.9)
Employment status	Employed	51 (22.5)
	Not Employed	12 (5.3)
	Retired	148 (65.2)
	Other	15 (6.6)
*Qualifications***	Professional Qualification	61 (26.9)
	Degree or Higher Degree	40 (17.6)
	A levels or equivalent	50 (22.0)
	GCSE/O Levels or equivalent	79 (34.8)
	No qualifications	39 (17.2)
Annual household income	£0-14,999	55 (24.2)
	£15-24,999	56 (24.7)
	£25-49,999	73 (32.2)
	£50-74,999	14 (6.2)
	Over £75,000	6 (2.6)
Self-reported health status	Very Good	58 (25.6)
	Good	99 (43.6)
	Fair	54 (23.8)
	Poor	12 (5.3)
	Very Poor	4 (1.8)
Residence	Rural	103 (45.4)
	Urban	120 (52.9)
County	Lincolnshire	126 (55.5)
	Leicestershire	80 (35.2)
	Northamptonshire	5 (2.2)
	Nottinghamshire	3 (1.3)
	Derbyshire	2 (0.9)
	Rutland	2 (0.9)
	Other	5 (2.0)
Primary Cancer Type	Breast	73 (32.2)
	Urological	53 (23.3)
	Skin	18 (7.9)
	Head and Neck	13 (5.7)
	Gynaecological	10 (4.4)
	Lower Gastrointestinal	30 (13.2)
	Haematological	10 (4.4)
	Upper Gastrointestinal	11 (4.8)
	Lung	6 (2.6)
	Sarcoma	1 (0.4)

**Percentages may not total 100% due to missing values. **Percentages add to more than 100% because participants could select more than one option*

5.3 Rural-Urban Classifications

The residence of participants was defined using the UK Office for National Statistics (ONS) RUC 2011 Rural Urban Classifications (Bibby and Brindley, 2013). From the total sample, fifty three per cent (N=120) of respondents resided in an urban area, of which the overwhelming majority (N=116) were in an area that could be classed as an urban city and town. Forty five per cent (N=103) of participants lived in a rural area, with nineteen per cent (N=43) of the total sample residing in an area categorised as rural town and fringe and eighteen per cent (N=40) in an area categorised as rural village. Full rural-urban classifications of respondents are reported in Table 5.2.

Table 5.2 Rural-Urban Classifications

Classifications*	***n* (%)****
A1: Urban major conurbation	1 (0.4)
C1: Urban city and town	116 (51.1)
C2: Urban city and town in a sparse setting	3 (1.3)
Total Urban (N=120)***	
D1: Rural town and fringe	43 (18.9)
D2: Rural town and fringe in a sparse setting	1 (0.4)
E1: Rural village	40 (17.6)
E2: Rural village in a sparse setting	4 (1.8)
F1: Rural hamlet and isolated dwellings	14 (6.2)
F2: Rural hamlet and isolated dwellings in a sparse setting	1 (0.4)
Total Rural (N=103)***	

**UK Office for National Statistics (ONS) RUC2011 Rural Urban Classifications*
***Percentages do not total 100% due to missing values.*
**** Total N does not equal 227 due to missing data.*

5.4 Health-Promoting Lifestyle Profile II (HPLP-II)

The Health-Promoting Lifestyle Profile II (Walker et al, 1995) was used to assess a range of behaviours that linked with a health-promoting lifestyle and how frequently people affected by cancer from this sample practiced these behaviours. The instrument is categorised into six-health promoting lifestyle subscales: (1) nutrition; (2) physical activity; (3) interpersonal relations; (4) health responsibility; (5) stress management and (6) spiritual growth. The frequencies and percentages for each subscale are reported below.

5.4.1. HPLP-II: Nutrition

For health-promoting nutrition behaviours, fifty one per cent (N=114) of the respondents said that they often or routinely chose a diet low in fat, saturated fat, and cholesterol. In terms of

eating fruit on a daily basis, thirty eight per cent (N=85) of participants reported that they never or only sometimes ate 2-4 servings. Respondents were asked how frequently they ate 3-5 servings of vegetables and sixty nine per cent (N=156) reported that they often or routinely do this each day. Full nutritional behaviours are reported in Table 5.3.

Table 5.3 Nutritional Behaviours

	Never	Sometimes	Often	Routinely	Total *N*
Choose a diet low in fat, saturated fat, and cholesterol	27 (11.9)	83 (37.1)	61 (27.2)	53 (23.7)	224
Limit use of sugars and food containing sugar	20 (8.8)	57 (25.7)	67 (30.2)	78 (35.1)	222
Eat 6-11 servings of bread, cereal, rice and pasta each day	136 (61.5)	52 (23.5)	24 (10.9)	9 (4.1)	221
Eat 2-4 servings of fruit each day	27 (12.1)	58 (25.9)	57 (25.4)	82 (36.6)	224
Eat 3-5 servings of vegetables each day	18 (8.0)	50 (22.3)	72 (32.1)	84 (37.0)	224
Eat 2-3 servings of milk yogurt or cheese each day	29 (12.9)	56 (24.9)	62 (27.6)	78 (34.7)	225
Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and nuts group each day.	23 (10.2)	58 (25.8)	64 (28.4)	80 (35.6)	225
Read labels to identify nutrients, fats, sodium content in packaged food.	68 (30.1)	63 (27.9)	46 (20.4)	49 (21.7)	226
Eat breakfast	15 (6.6)	14 (6.2)	25 (11.1)	172 (76.1)	226

Values represent frequencies, % reported in brackets. Total N is different due to missing data.

5.4.2. HPLP-II: Physical Activity

In relation to physical activity, forty two per cent (N=95) of participants reported that they never follow a planned exercise programme and thirty four per cent (N=78) reported that they never exercise vigorously for twenty or more minutes at least three times a week. With regard to taking part in light to moderate physical activity, forty nine per cent (N=112) of the respondents reported that they do this often or routinely. Forty per cent (N=90) reported that they routinely get exercise during usual daily activities. The full physical activity behaviours are presented in Table 5.4.

Table 5.4 Physical Activity Behaviours

	Never	Sometimes	Often	Routinely	Total *N*
Follow a planned exercise programme	95 (42.2)	71 (31.6)	31 (13.8)	28 (12.4)	225
Exercise vigorously for 20 or more minutes at least three times a week	78 (34.5)	58 (25.7)	30 (13.3)	60 (26.5)	226
Take part in light to moderate physical activity	53 (23.5)	61 (27.0)	38 (16.8)	74 (32.7)	226
Take part in leisure-time physical activities	106 (47.1)	49 (21.8)	26 (11.6)	44 (19.6)	225
Do stretching exercises at least 3 times per week	107 (47.8)	57 (25.4)	27 (12.1)	33 (14.7)	224
Get exercise during usual daily activities	31 (13.8)	47 (20.9)	57 (25.3)	90 (40.0)	225
Check my pulse rate when exercising	177 (78.3)	28 (12.4)	14 (6.2)	7 (3.1)	226
Reach my target heart rate when exercising	135 (62.2)	47 (21.7)	18 (8.3)	17 (7.8)	217

Values represent frequencies, % reported in brackets. Total N is different due to missing data.

5.4.3. HPLP-II: Interpersonal Relations

The participants were asked nine questions in relation to interpersonal relations and forty two per cent (N=95) reported that they only sometimes discuss problems and concerns with people close to them. Fifty seven per cent (N=128) felt that they could routinely maintain meaningful and fulfilling relationships with others. Thirty five per cent (N=79) said that they routinely spent time with close friends. Thirty per cent (N=66) of respondents reported that they were never able to find ways to meet their needs for intimacy. Twenty one per cent (N=46) of the sample said that they could never get support from a network of caring people. Table 5.5 presents the full frequencies and percentages for the responses to questions on interpersonal relations.

Table 5.5 Interpersonal Relations Behaviours

	Never	Sometimes	Often	Routinely	Total *N*
Discuss my problems and concerns with people close to me	12 (5.3)	95 (42.2)	62 (27.6)	56 (24.9)	225
Praise other people easily for their achievements	4 (1.8)	36 (16.1)	81 (36.2)	103 (46.0)	224
Maintain meaningful and fulfilling relationships with others	3 (1.3)	31 (13.7)	64 (28.3)	128 (56.6)	227
Spend time with close friends	10 (4.4)	71 (31.6)	65 (28.9)	79 (35.1)	225
Find it easy to show concern, love and warmth to others	3 (1.3)	36 (15.9)	78 (34.5)	109 (48.2)	226
Touch and am touched by people I care about	3 (1.4)	43 (19.5)	73 (33.2)	101 (45.9)	220
Find ways to meet my needs for intimacy	66 (30.4)	73 (33.6)	45 (20.7)	33 (15.2)	217
Get support from a network of caring people	46 (20.5)	51 (22.8)	67 (29.9)	60 (26.4)	224
Settle conflicts with others through discussion and compromise	18 (8.0)	76 (33.9)	74 (33.0)	56 (25.0)	224

Values represent frequencies, % reported in brackets, Total N is different due to missing data.

5.4.4 HPLP-II: Health Responsibility

Respondents were asked nine questions in relation to health responsibility and forty one per cent (N=92) said that they only sometimes report any unusual signs or symptoms to a physician or other health professional. In addition, thirty eight per cent (N=85) reported that they sometimes question health professionals in order to understand their instructions. With regard to inspecting their bodies on a monthly basis for physical changes, over half (N=120) said they did this often or routinely. Over a third (N=82) of respondents reported never asking for information from health professionals about how to take good care of themselves. The overwhelming majority (N=197) of the sample said that they never attended educational programmes in relation to personal health care. Forty seven per cent (N=105) of the participants said that they had never sought guidance or counselling even if they felt it was necessary. Full health responsibility behaviours are reported in Table 5.6.

Table 5.6 Health Responsibility Behaviours

	Never	Sometimes	Often	Routinely	Total *N*
Report any unusual signs or symptoms to a physician or other health professional	3 (1.3)	92 (40.7)	53 (23.5)	78 (34.5)	226
Read or watch TV programmes about improving health	53 (23.9)	121 (54.5)	34 (15.3)	14 (6.3)	222
Question health professionals in order to understand their instructions	27 (12.2)	85 (38.3)	53 (23.9)	57 (25.7)	222
Get a second opinion when I question my health care provider's advice	116 (52.3)	80 (36.0)	13 (5.9)	13 (5.9)	222
Discuss my health concerns with health professionals	16 (7.1)	116 (51.8)	45 (20.1)	47 (21.0)	224
Inspect my body at least monthly for physical changes/danger signs	39 (17.6)	62 (28.1)	49 (22.2)	71 (32.1)	221
Ask for information from health professionals about how to take good care of myself	82 (36.6)	97 (43.3)	26 (11.6)	19 (8.5)	224
Attend educational programmes on personal health care	197 (87.6)	24 (10.7)	2 (0.9)	2 (0.9)	225
Seek guidance or counselling when necessary	105 (46.9)	69 (30.8)	21 (9.4)	29 (12.9)	224

Values represent frequencies, % reported in brackets. Total N is different due to missing data.

5.4.5 HPLP-II: Stress Management

Participants were asked eight questions that referred specifically to stress management behaviours. Firstly, they were asked whether they felt they got enough sleep and over half (N=125) reported that they often or routinely did. Furthermore, seventy nine per cent (N=178) said that they often or routinely accepted things in their life which they felt they could not change. Forty one per cent (N=94) reported that they sometimes concentrate on pleasant thoughts at bedtime. With regard to using specific methods to control stress, forty seven per cent (N=105) of the respondents said they never did this and fifty six per cent (N=125) said that they never or only sometimes paced themselves to prevent tiredness. Nine per cent (N=21) of participants reported often or routinely practicing relaxation or meditation for 15-20 minutes on a daily basis. The full stress management behaviours are presented in Table 5.7.

Table 5.7 Stress Management Behaviours

	Never	Sometimes	Often	Routinely	Total *N*
Get enough sleep	27 (12.1)	72 (32.1)	68 (30.4)	57 (25.4)	224
Take some time for relaxation each day	6 (2.7)	71 (31.4)	71 (31.4)	78 (34.5)	226
Accept those things in my life which I cannot change	8 (3.5)	41 (18.1)	73 (32.2)	105 (46.3)	227
Concentrate on pleasant thoughts at bedtime	21 (9.3)	94 (41.4)	67 (29.5)	45 (19.8)	227
Use specific methods to control my stress	105 (47.1)	67 (30.0)	26 (11.7)	25 (11.2)	223
Balance time between work and play	40 (18.4)	56 (25.8)	55 (25.3)	66 (30.4)	217
Practice relaxation or meditation for 15-20 minutes daily	152 (67.3)	53 (23.5)	10 (4.4)	11 (4.9)	226
Pace myself to prevent tiredness	39 (17.5)	86 (38.6)	56 (25.1)	42 (18.8)	223

Values represent frequencies, % reported in brackets. Total N is different due to missing data.

5.4.6 HPLP-II: Spiritual Growth

Finally, there were nine questions on the spiritual growth subscale. Almost three quarters (N=162) of the total sample reported that they often or routinely felt that their life had purpose. Additionally, seventy six per cent (N=172) reported that they often or routinely looked forward to the future. Twenty five per cent (N=55) of participants said that they never worked towards long-term goals in their life. Fifty eight per cent (N=129) reported that they often or routinely found each day interesting and challenging and eighty four per cent (N=187) said that they often or routinely were aware of what was important to them in their life. Forty nine per cent (N=108) of the sample reported never feeling connected with a force greater than themselves and sixty three per cent (N=143) said that they never or only sometimes exposed themselves to new experiences and challenges. The full frequencies and percentages for spiritual growth behaviours are reported in Table 5.8.

Table 5.8 Spiritual Growth Behaviours

	Never	Sometimes	Often	Routinely	Total *N*
Feel I am growing and changing in positive ways.	35 (15.8)	94 (42.3)	60 (27.0)	33 (14.9)	222
Believe that my life has purpose	10 (4.5)	50 (22.5)	67 (30.2)	95 (42.8)	222
Look forward to the future	10 (4.4)	45 (19.8)	66 (29.1)	106 (46.7)	227
Feel content and at peace with myself	12 (5.3)	70 (30.8)	82 (36.1)	63 (27.8)	227
Work toward long-term goals in my life	55 (24.8)	71 (32.0)	55 (24.8)	41 (18.5)	222
Find each day interesting and challenging	13 (5.8)	81 (36.3)	70 (31.4)	59 (26.5)	223
Am aware of what is important to me in life	5 (2.2)	32 (14.3)	67 (29.9)	120 (53.6)	224
Feel connected with some force greater than myself	108 (49.5)	41 (18.8)	33 (15.1)	36 (16.5)	218
Expose myself to new experiences and challenges	42 (18.6)	101 (44.7)	52 (23.0)	31 (13.7)	226

Values represent frequencies, % reported in brackets. Total N is different due to missing data.

5.5 HPLP-II Mean Scores

Table 5.9 shows the mean scores of the participants' health-promoting lifestyles. Out of the six subscales previously reported above, respondents scored highest in interpersonal relations with a mean value of 2.94±0.58 (range 1.11-4.00) and lowest in physical activity with a mean value of 2.08±0.73 (range 1.00-4.00). The mean value for the total HPLP II scale was 2.55±0.46 (range 1.38-4.00).

When comparing between male and female respondents, females (2.80±0.56) reported higher health behaviours in relation to nutrition compared to males (2.65±0.60) although this was not significant at $p<0.01$. With regard to interpersonal relations, females (3.05±0.56) scored significantly higher ($p<0.01$) compared to male participants (2.81±0.60). Males (2.52±0.54) reported a higher engagement with stress management behaviours compared to females (2.47±0.55), however, this was not significant. In addition, there were no significant differences when comparing between gender across the remaining subscales and the HPLP-II

as whole. Interestingly, there was no linear association (*r = -.158*) with age and health-promoting behaviours.

Table 5.9 Participant's Health-Promoting Lifestyle Profile Total and Subscale Scores

HPLP II and subscales	(χ) ± SD	Range	***N*=**
Total HPLP II (52 items)	2.55 (.46)	1.38-4.00	160
Health Responsibility (9 items)	2.16 (.53)	1.00-4.00	205
Physical Activity (8 items)	2.08 (.73)	1.00-4.00	211
Nutrition (9 items)	2.73 (.59)	1.00-4.00	216
Spiritual Growth (9 items)	2.72 (.63)	1.22-4.00	204
Interpersonal Relations (9 items)	2.94 (.58)	1.11-4.00	206
Stress Management (8 items)	2.49 (.55)	1.25-4.00	210

HPLP, Health promotion life-style Profile**;** (χ), mean; ± SD, standard deviation. Total N is different due to missing data.

5.6 Patient Activation Measure (PAM-13)

After the questions on health-promoting behaviours, participants were asked thirteen questions on patient activation. Patient activation can be defined as the knowledge, skills, and confidence a person has to manage their health and health care (Hibbard et al, 2004). To do this, the short form of the Patient Activation Measure (PAM-13) developed by Hibbard et al, (2005) was used to calculate patient activation amongst this sample of people affected by cancer.

In Table 5.10, the frequencies and percentages of the responses to each individual statement on the PAM-13 are reported. Respondents were asked to indicate how much they agreed or disagreed with each statement as it applied to them personally. The overwhelming majority (96.5%) of respondents agreed or agreed strongly that they were responsible for taking care of their health. Interestingly, nearly one fifth (19%) of participants disagreed or disagreed strongly that they were confident that they could help prevent or reduce problems associated with their health. One fifth (20.7%) of respondents disagreed or disagreed strongly that they could maintain lifestyle changes like healthy eating or exercising. Just over a quarter (26%) of participants disagreed or disagreed strongly that they were not confident that they could work out solutions when new problems arose with their health. Finally, one quarter (25.1%) of respondents disagreed or disagreed strongly that they were confident they could maintain lifestyle changes, like healthy eating and exercising, even during times of stress.

Based on the responses to the thirteen items each participant receives a PAM score that can range from 0-100 with higher scores indicative of higher activation. The mean score of the 13 item PAM for all participants was 61.50±13.51 (range 33.00-100). Females (62.57±14.44) reported higher patient activation than males (60.36±12.41), however, this was not statistically significant and there was also no significant association between age and patient activation (*r = -.029)*.

The individual PAM scores can be converted into four levels of activation which represent a developmental progression from being passive to one's health to being proactive (Hibbard et al, 2005). Firstly, level 1 (0.0-47.0) suggests that the participant may not yet understand that the patient's role is important in the care process, they tend to be passive and feel overwhelmed by managing their health. Level 2 (47.1-55.1) indicates that the respondent lacks the confidence and knowledge to take action and manage their health. Level 3 (55.2-72.4) suggests that the participant is beginning to engage in recommended health behaviours but may still lack the confidence and skill to support these behaviours. Finally, level 4 (72.5-100) indicates that the respondent is proactive about their health and engages in several recommended health behaviours.

In this sample, half of respondents (49.8%) were categorised as level 3 indicating that they were beginning to engage in recommended health behaviours but may still lack the confidence and skill to support these behaviours. Twelve per cent (N=26) were level 1 of patient activation indicating that they tend to feel overwhelmed by self-managing their health and may not understand their role in the care process. Nineteen per cent (N=44) were level 4 indicating that these individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors. Full activation levels are reported in Table 5.11.

Table 5.10 PAM-13: Managing Your Health and Health Care

	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
I am the person who is responsible for taking care of my health (N=226)	2 (0.9)	3 (1.3)	96 (42.3)	123 (54.2)	2 (0.9)
Taking an active role in my own health care is the most important thing that affects my health (N=227)	3 (1.3)	13 (5.7)	113 (49.8)	93 (41.0)	5 (2.2)
I am confident I can help prevent or reduce problems associated with my health (N=224)	4 (1.8)	39 (17.2)	135 (59.5)	43 (18.9)	3 (1.3)
I know what each of my prescribed medications do (N=227)	-	11 (4.8)	109 (48.0)	85 (37.4)	22 (9.7)
I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself (N=225)	-	14 (6.2)	134 (59.0)	77 (33.9)	-
I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask (N=226)	4 (1.8)	16 (7.0)	115 (50.7)	90 (39.6)	1 (0.4)
I am confident that I can carry out medical treatments I may need to do at home (N=226)	3 (1.3)	13 (5.7)	112 (49.3)	83 (36.6)	15 (6.6)
I understand my health problems and what causes them (N=226)	2 (0.9)	21 (9.3)	137 (60.4)	60 (26.4)	6 (2.6)
I know what treatments are available for my own health problems (N=226)	2 (0.9)	30 (13.2)	127 (55.9)	52 (22.9)	15 (6.6)
I have been able to maintain lifestyle changes, like healthy eating or exercising (N=225)	10 (4.4)	37 (16.3)	111 (48.9)	54 (23.8)	13 (5.7)
I know how to prevent problems with my health (N=224)	5 (2.2)	37 (16.3)	149 (65.6)	27 (11.9)	6 (2.6)
I am confident I can work out solutions when new problems arise with my health (N=225)	4 (1.8)	55 (24.2)	135 (59.5)	24 (10.6)	7 (3.1)
I am confident I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress (N=225)	5 (2.2)	52 (22.9)	125 (55.1)	37 (16.3)	6 (2.6)

Column cells refer to frequencies, % reported in brackets

Table 5.11 Participants' Patient Activation Score Categorised

Activation Score Categorised*	N (%)**
Level 1: Starting to Take a Role	26 (11.5)
Level 2: Building Knowledge and Confidence	32 (14.1)
Level 3: Taking Action	113 (49.8)
Level 4: Maintaining Behaviour	44 (19.4)

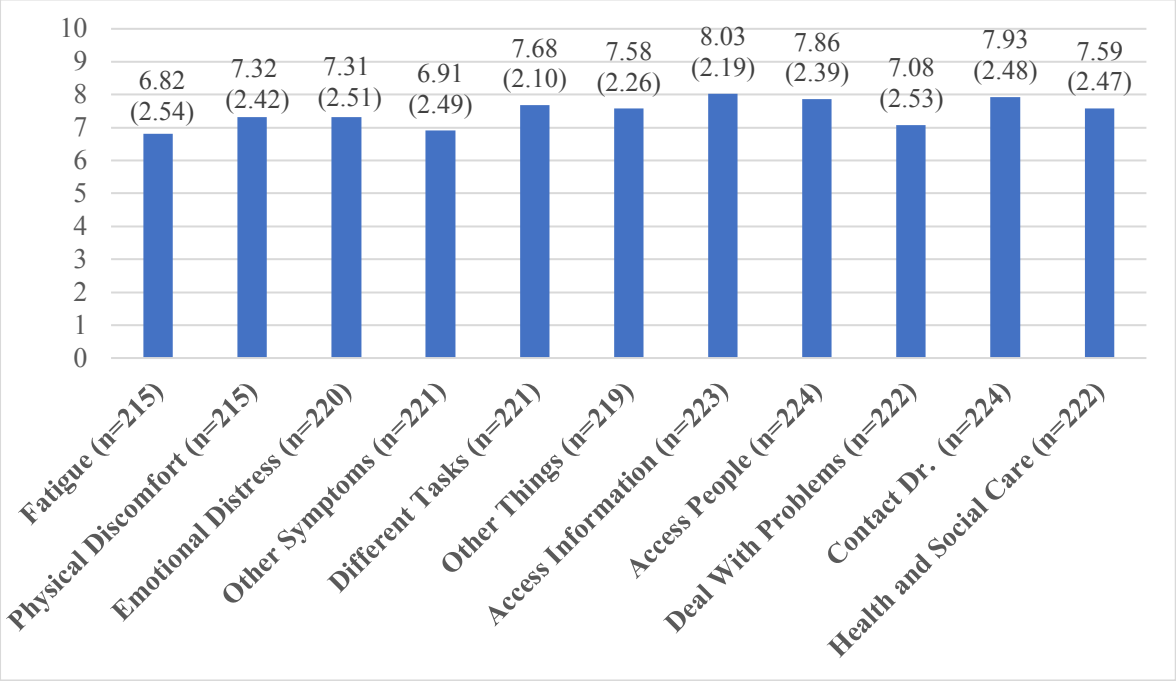
**Level 1 (scores 0-47.0); Level 2 (scores 47.1-55.1); Level 3 (scores 55.2-67.0); Level 4 (scores 67.1-100)*
***Percentages do not total 100% due to missing values.*

5.7 Cancer Survivors Self-Efficacy Scale (CSSES)

Following the questions on patient activation, participants rated their confidence to perform eleven self-management behaviours (1=not at all confident to 10=totally confident). This was done using the 11 item Cancer Survivors Self-efficacy Scale (Foster et al, 2013). The scale comprised of the Self-Efficacy for Managing Chronic Disease Six-Item Scale (Lorig et al, 2001) with an additional five items that explicitly refer to managing the effects of cancer and its treatment. A mean score was calculated for the scale as a whole, as well as, each individual item and a higher score was indicative of high self-efficacy.

The mean score on the Self-efficacy for Managing Chronic Disease 6-item Scale was 7.23±2.05 (range 1.00-10.00). The mean score on the Cancer Survivors Self-Efficacy 11-item scale was 7.44±1.91 (range 1.73-10.0). In line with patient activation, there were no statistically significant differences between males (7.38±1.84) and females (7.50±1.98) when it came to self-efficacy, as well as, no significant relationship between age and self-efficacy (r=-.022). Self-efficacy to manage specific tasks was lowest when respondents were asked how confident they were that they could keep fatigue from interfering with the things they wanted to do (6.82±2.54). Self-efficacy was also low in terms of confidence to keep any other symptoms or health problems the respondent had from interfering with things they wished to do (6.91±2.49). Respondents were most confident when it came to accessing information about their cancer and the effects of diagnosis and treatment (8.03±2.19). Respondents also scored high on confidence to contact their doctor about problems caused by cancer and its treatment (7.93±2.48). Full self-efficacy mean scores can be found in Figure 5.1.

Figure 5.1 Mean Values of Self-efficacy to Self-manage



Note: Mean values are presented, figures in brackets refer to the standard deviation. Higher score indicates higher self-efficacy. Total N is different due to missing data.

5.8 Bivariate Analysis: HPLP-II; PAM; Cancer Survivors Self-Efficacy

In order to assess the direction and strength of the relationships between the continuous-level outcome variables, a bivariate Pearson's *r* and Spearman's Rho correlation analysis was conducted. The analysis revealed a moderate positive correlation (r=.548) between HPLP-II and the PAM which was statistically significant ($p<0.01$), suggesting that respondents who practice more health promoting behaviours were more activated. Again, HPLP-II was positively correlated (r=.466) with Cancer Survivors Self-Efficacy ($p<0.01$), suggesting that those who engaged with health promoting behaviours had higher self-efficacy to perform specific self-management activities. Finally, there was a significant ($p<0.01$) moderate positive association (r=.483) between patient activation and self-efficacy, suggesting that more activated patients have greater confidence to manage their health and perform self-management tasks. Therefore, in response to RQ4, there is a moderate positive relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy when correlated with one another. Therefore, the fourth null hypothesis outlined at the beginning of the chapter that stated *'there is no relationship between health-promoting behaviours, patient activation and*

cancer-related self-efficacy' can be rejected. Full results of the correlation analysis are reported in Table 5.12.

Table 5.12 Bivariate Correlational Analysis of HPLP-II; PAM-13; CSSES

	HPLP-II	**PAM-13**	**CSSES**
HPLP-II	-	**.548**** *N=153*	**.466**** *N=147*
PAM-13	**.548**** *N=153*	-	**.483**** *N=202*
CSSES	**.466**** *N=147*	**.483**** *N=202*	-

Values represent Pearson's *r* and Spearman's Rho correlation coefficient **Correlation is significant at p<0.01

5.9 Further Information: Qualitative Comments

At the end of the questionnaire, respondents were asked to consider how they manage their health and health care, and if there was anything else they would like to add regarding their experience to write in the open-text box. They were asked the following question*: 'Thinking about how you manage your health and health care, if there is anything else you would like to tell us about your experience, please write in the box below.'* Fifty six per cent (N=128) of the total sample (N=227) reported additional information about their experience of cancer. Four themes emerged from the analysis of the free text comments (1) The idea of "moving on" (2) Luck (3) Self-management and (4) Support. These are reported below:

5.9.1 The idea of "Moving On"

The main overarching theme taken from the open text data was the concept of the participants "moving on" from cancer and developing a meaningful life for themselves following diagnosis and treatment. For most, this incorporated making adjustments to their physical, social, psychological, spiritual and emotional wellbeing. Many participants appeared to give a personal narrative of their cancer experience from diagnosis, to treatment and then ultimately "moving on" and their personal journey to recovery from cancer.

The idea of "recovery" from cancer was prominent. This may incorporate both clinical and personal recovery. Clinical referring to being free of symptoms, side effects, no longer

receiving treatment or follow-up care, as well as in "remission". The personal relating to the individual "moving on" and building a meaningful life for themselves after their cancer experience. One participant below felt that putting their cancer in the past helped with their recovery:

> *"I was lucky that my nephrectomy completely removed my tumour. Since then, I feel the best medicine for me is to put it behind me."* Female, 67, Urological Cancer, Resident in a Rural Area.

5.9.2 'Good Fortune'

Another theme from the analysis of the data was "good fortune". Participants gave an account of their outlook for the future, detailing both positivity about "moving on", together with inevitable apprehensions about the future. Aside from this, many participants stated that they were "glad to still be alive", and they "count my blessing" and "consider myself very lucky" as evident below:

> *"As I have been lucky to survive lung cancer I do treat my life with more respect and try to eat sensibly and take regular exercise to ensure I stay as fit as possible. The 6 monthly checks I receive are very important in ensuring I remain cancer free and I am so grateful that the monitoring lasts for 5 years. Ideally I would like the checks to go on longer for added confidence."* Male, 76, Lung Cancer, Resident in an Urban Area.

> *"I am extremely lucky my experience with cancer was a very mild one. I am extremely lucky and blessed to have an early call up at 47 for a mammogram - I pray and thank God it wasn't at 50+ like some unfortunate friends of mine…I am physically very fit and well vegetarian and exercise 5+ times a week!"* Female, 50, Breast Cancer, Resident in a Rural Area.

5.9.3 Self-Management

The questionnaire may have "primed" the participant to write about self-management which could account for why qualitative responses to this section were prominently related to the behavioural and psychological self-management of the participants.

The behavioural aspects of self-management encompass adjustments made by the participants to their health behaviours such as leading an active lifestyle, increasing exercise and making

changes to their diet and nutrition. The psychological aspect of self-management encompasses participants building their emotional resilience and strategies for this (e.g. meditation, mindfulness), their emotions and attitudes towards their cancer experience, including their outlook on life after cancer, and their attitudes towards managing their health and health care. The participant below explains how activities such as yoga and meditation as well as a meat free diet have enhanced her recovery:

> *"I have started and maintained a holistic and natural lifestyle, this has been through my own research, reading and the internet. I think that a holistic approach is a good way of feeling like you have regained control of your life. I think that things like diet, meditation, yoga etc. should be promoted much more by the cancer care team. Places like Maggie's [Centre] have proved invaluable in my mental recovery. Reflexology (Privately) during my treatment also helped me to manage side effects (physical) and also Reiki has helped the mental side of recovery. I now have a gluten and dairy free lifestyle without meat and concentrate heavily on nutrition."* Female, 40, Gynaecological Cancer, Resident in a Rural Area.

Another participant below who was diagnosed with Upper Gastrointestinal Cancer explains how keeping track of their food intake and practicing daily meditation have improved their ability to cope with problems, they stated:

> *"Keeping a food diary helped to control acid reflux especially at night. Attending a mindfulness course run by the NHS has totally changed my view on life. My husband and I meditate every day and feel able to cope with most problems."* Female, 74, Upper Gastrointestinal Cancer, Resident in an Urban Area.

However, not all participants reported positive experiences of self-management, the below respondent explains how they are having difficulty with pain, fatigue and emotional management, she reported:

> *"In constant pain. Acute fatigue. Psychological after effects terrible. Still struggle to cope."* Female, 50, Breast Cancer, resident in an Urban Area

5.9.4 Support

The final theme extracted from the data incorporates the participants identifying their main sources of support throughout their cancer journey, some of which the participants stated they "could not have done it without them" and in some cases have reported they subjectively feel they owe their life to. This theme was divided into two sub themes.

5.9.4.1 Clinical

Firstly, participants reported both positive and negative experiences of clinical support as evident below:

> *"[Name removed] hospital have been great from diagnosis to now ongoing follow ups. Many thanks to my GP at [name removed] for pushing for my diagnosis. Great work. God Bless You All x"* Male, 57, Lower Gastrointestinal Cancer, Resident in a Rural Area.

> *"Biggest difficulty is dealing with the initial diagnosis. It took me several months before I did not think of my cancer every day. My consultant is great and gave me hope. I try to enjoy every day. So far all is OK - let's hope it stays that way."* Male, 67, Skin Cancer, Resident in an Urban Area.

> *"I think that because the operation to have a mastectomy and immediate aftercare in the hospital was so poor it has seriously knocked my confidence and most of the time I feel isolated and helpless. No one understands how difficult I am finding coping with everyday life. I should have another operation, but keep putting it off because my original experience was so bad. I can't face going through it again and feel trapped."* Female, 55, Breast Cancer, resident in a Rural Area.

Accessing support throughout the cancer journey was problematic, particularly relating to travel:

> *"Although my treatment was not stressful the need to travel into the city centre for a specific time was! (40+ appointments)."* Male, 74, Urological Cancer, Resident in an Urban Area

"I attended a Pink Ribbon exercise group held at the David Lloyd Sport Centre twice a week for six weeks after treatment ended. This was very good but access from [name removed] was not easy. I realise there are support groups held in [name removed] but transport problems make it quite difficult." Female, 67, Breast Cancer, Resident in a Rural Area.

5.9.4.2 Non-clinical

Non-clinical support from friends and family was an important factor for many of the participants. The respondent below explains how they were disappointed with the lack of gender specific support for males and how they felt family support was crucial to recovery, he stated:

"Was treated with respect - continues with reviews attended Macmillan survivors course - 6 weeks which was mostly positive - disappointed by unavailability of men only groups. Family support most important aspect of recovery." Male, 62, Head and Neck Cancer, Resident in a Rural Area

Furthermore, the respondents below explain how they have a supportive network of non-clinical support through their family and friends:

"My attitude is very positive and am lucky to have a supportive family (though not nearby) and lots of friends who are and I have been open with them all about my situation. We all know no one lives forever - c'est la vie!" Female, 80, Breast Cancer, Resident in a Rural Area

"Have tried hard to continue my way of life, not allowing side effects to ruin my life. Have many family and friends in support." Urological, Male, 72, Resident in an Urban Area

"…Lots of support in all sorts of ways from friends in the village was certainly helpful and comforting during treatment…" Male, 69, Haematological Cancer, Resident in a Rural Area.

5.10 Rural-Urban Comparisons

5.10.1 Characteristics of Participants

As previously mentioned, forty five per cent (N=103) of the total sample (N=227) were resident in a rural area (N=103) and fifty three per cent (N=120) in an urban area. Four participants did not input their postcode on the questionnaire, therefore their residence was coded as missing.

The mean age of urban respondents was 67.05 ± 11.53 (range 40-90) and was only moderately higher than the mean age of rural respondents which was 66.30 ± 10.83 (range 26-89). Sixty per cent (N=62) of rural respondents were female compared to forty eight per cent (N=57) of urban and fifty two per cent (N=63) of urban respondents were male compared to forty per cent (N=41) of those residing in rural areas. In terms of ethnicity, those who were not white British were Indian (N=4), African (N=1), and Caribbean (N=1) and resided in an urban area. Eighty two per cent (N=98) of urban respondents reported their religion as Christian compared to seventy seven per cent (N=79) of rural respondents. Twenty five per cent (N=30) of urban respondents reported living alone compared to nine per cent (N=9) of rural respondents. Eighty four per cent (N=86) of rural participants reported being married compared to sixty six per cent (N=79) of urban participants. When asked about employment status, sixty seven per cent (N=69) of rural participants said they were retired compared to sixty three per cent (N=75) of urban participants. Twenty five per cent (N=30) of those in urban areas reported having no qualifications compared to eight per cent (N=8) of those in rural areas. Participants from rural areas reported having higher annual household income than those in urban areas with forty seven per cent (N=48) saying their income was above £25,000 compared to thirty six per cent (N=43) from urban areas. Full rural-urban comparison of participant characteristics can be found in Table 5.13.

Table 5.13 Characteristics of Participants: Rural-Urban Comparison

		Rural Total N=103 n (%)	***Urban Total N=120 n (%)***
Age	25-34	1 (1.0)	0 (0.0)
	35-44	2 (1.9)	4 (3.3)
	45-54	12 (11.7)	15 (12.5)
	55-64	24 (23.3)	26 (21.7)
	65-74	42 (40.8)	48 (40.0)
	Over 75	22 (21.4)	27 (22.5)
Gender	Female	62 (60.2)	57 (47.5)
	Male	41 (39.8)	63 (52.5)
	Other gender identity	0 (0)	0 (0)
Ethnicity	White British	103 (100)	114 (95.0)
	Indian	0 (0)	4 (3.3)
	African	0 (0)	1 (0.9)
	Caribbean	0 (0)	1 (0.9)
Religion	Christian	79 (76.7)	98 (81.7)
	No Religion	19 (18.4)	17 (14.2)
	Hindu	0 (0)	2 (1.7)
	Muslim	0 (0)	1 (0.8)
	Sikh	0 (0)	1 (0.8)
	Any other religion	1 (1.0)	0 (0)
Living arrangements	Partner/Spouse/Family/Friends	92 (89.3)	89 (74.2)
	Alone	9 (8.7)	30 (25.0)
	Nursing home/Hospital/Long-term care home	0 (0)	1 (0.8)
Marital status	Married	86 (83.5)	79 (65.8)
	Living with partner	3 (2.9)	3 (2.5)
	Widowed	8 (7.8)	15 (12.5)
	Single	1 (1.0)	9 (7.5)
	Divorced/Separated	4 (3.9)	14 (11.7)
Employment status	Employed	21 (20.4)	30 (25.0)
	Not Employed	3 (2.9)	9 (7.5)
	Retired	69 (67.0)	75 (62.5)
	Other	9 (8.7)	6 (5.0)
*Qualifications***	Professional Qualification	30 (29.1)	30 (25.0)
	Degree or Higher Degree	19 (18.4)	20 (16.7)
	A levels or equivalent	24 (23.3)	26 (21.7)
	GCSE/O Levels or equivalent	35 (34.0)	43 (35.8)
	No qualifications	8 (7.8)	30 (25.0)
Annual household income	£0-14,999	23 (22.3)	31 (25.8)
	£15-24,999	19 (18.4)	36 (30.0)
	£25-49,999	36 (35.0)	35 (29.2)
	£50-74,999	7 (6.8)	7 (5.8)
	Over £75,000	5 (4.9)	1 (0.8)
Primary Cancer Type	Breast	39 (37.9)	34 (28.6)
	Urological	22 (21.4)	30 (25.2)
	Skin	8 (7.8)	10 (8.4)
	Head and Neck	7 (6.8)	6 (5.0)
	Gynaecological	6 (5.8)	4 (3.4)
	Lower Gastrointestinal	13 (12.6)	16 (13.4)
	Haematological	4 (3.9)	6 (5.0)
	Upper Gastrointestinal	3 (2.9)	8 (6.7)
	Lung	0 (0)	5 (4.2)
	Sarcoma	1 (1.0)	0 (0)

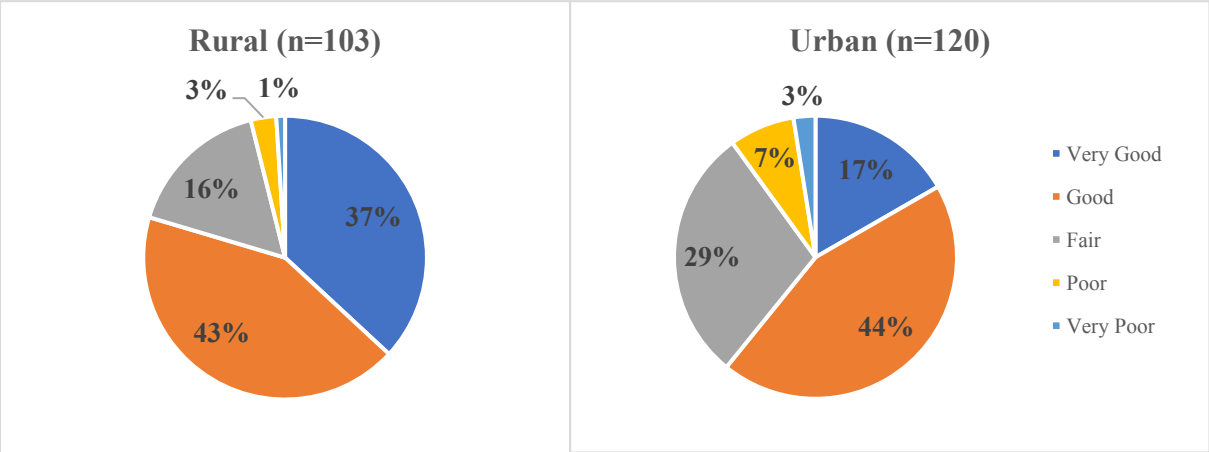
**Percentages may not total 100% due to missing values.*
***Percentages add to more than 100% because participants could select more than one option*

5.10.2 Self-Reported Health Status

Respondents were asked to self-report their current health status by answering the question, how is your health in general. The possible responses were 'Very Good', 'Good', 'Fair', 'Poor' and 'Very Poor'. In order to identify differences between rural and urban participants the results were compared using the pie chart below (see Figure 5.2). Thirty seven per cent (N=38) of rural respondents reported their health as very good compared to seventeen per cent (N=20) of urban respondents. Forty three per cent of rural (N=44) and forty four per cent of urban (N=53)

participants regarded their health as good. Twenty nine per cent (N=35) of urban respondents reported their health as fair compared to seventeen per cent (N=17) of rural respondents who selected this option. Finally, ten per cent (N=12) of urban participants self-reported their health as poor or very poor compared to 4 per cent (N=4) of rural participants. When comparing the means between rural and urban respondents, rural (4.11±0.85) respondents had significantly (*p<0.001*) higher self-reported health status compared to urban (3.65±0.93) respondents (MD 0.47; 95% CI 0.23, 0.70).

Figure 5.2 Self-Reported Health Status: Rural-Urban Comparison



5.10.3 HPLP-II

In terms of health-promoting behaviours, independent samples *t* tests revealed that participants who resided in rural areas had a significantly greater Health-Promoting Lifestyle Profile (*p<0.001*) compared to those in urban areas. Additionally, rural participants scored significantly higher than urban participants with regard to health responsibility (*p<0.01*); nutrition (*p<0.001*); spiritual growth (*p<0.01*); and interpersonal relationships (*p<0.001).* Rural participants engaged more with physical activity behaviours although this was not significant at *p<0.01*. There were no significant differences between rural and urban when it came to stress management. In response to RQ1 the results suggest that rural respondents engage with health-promoting behaviours more than those who reside in urban areas. Consequently, the first null hypothesis that stated *'there is no difference in health-promoting behaviours in people affected by cancer from rural and urban areas'* can be rejected. Full rural-urban comparisons of the Health Promoting Lifestyle Profile can be found in Table 5.14.

Table 5.14 HPLP II: Rural-Urban Comparison

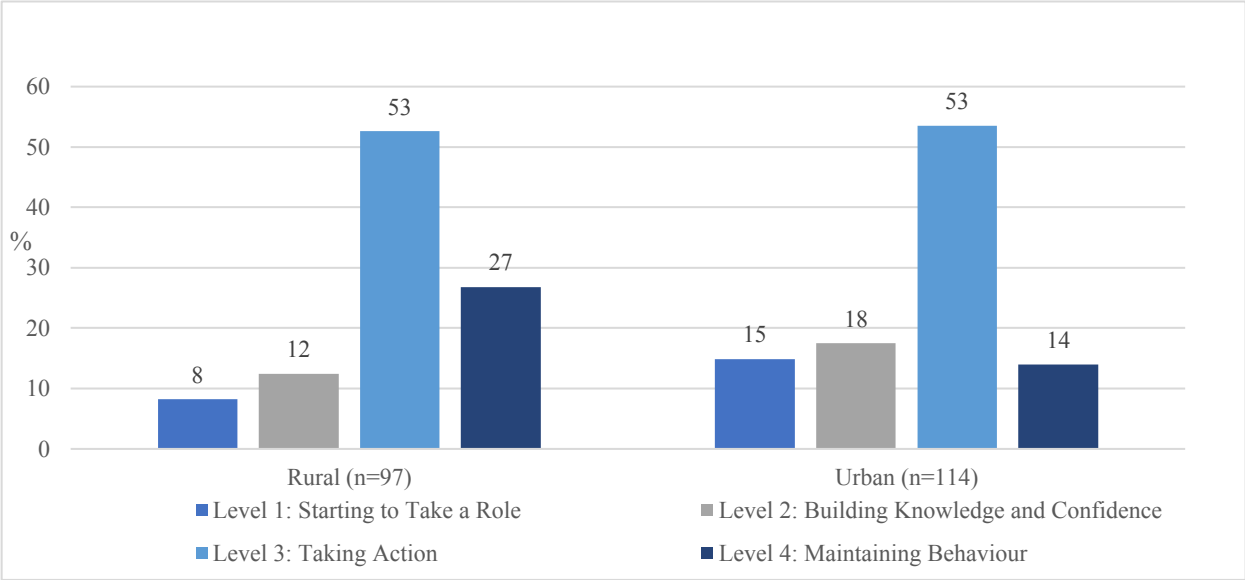
	Overall HPLP-II	Health Responsibility	Physical Activity	Nutrition	Spiritual Growth	Interpersonal Relationships	Stress Management
Residence							
Rural	**2.69*** **	**2.27** **	2.21	**2.88*** **	**2.86** **	**3.10*** **	2.51
	(0.44)	**(0.51)**	(0.71)	**(0.53)**	**(0.60)**	**(0.57)**	(0.55)
N=	72	95	92	100	90	94	96
Urban	2.41	2.04	1.98	2.59	2.60	2.80	2.46
	(0.42)	(0.50)	(0.71)	(0.60)	(0.64)	(0.55)	(0.53)
N=	87	108	116	113	111	110	112
T value	**4.122*** **	**3.241** **	2.256	**3.829*** **	**2.919** **	**3.818*** **	0.740
MD	**0.28**	**0.23**	0.22	**0.30**	**0.26**	**0.30**	0.05
95% CI	**0.14, 0.42**	**0.09, 0.37**	0.02, 0.42	**0.14, 0.45**	**0.08, 0.43**	**0.14, 0.45**	-0.09, 0.20

*The values are expressed as means (SD), and Independent Samples t-Tests were conducted. **P<0.01, ***P<0.001*
MD denotes the mean difference between groups. 95% CI represents the 95 % Confidence Interval.

5.10.4 PAM-13

When comparing the four levels of patient activation, between rural and urban respondents, 14 per cent of urban respondents (N=16) were level four (maintaining behaviour) compared to 27 per cent (N=26) of rural respondents. Furthermore, fifteen per cent (N=17) of urban respondents were categorised as level one (starting to take a role) compared to eight per cent (N=8) of rural respondents. Eighteen per cent (N=20) of urban respondents were categorised as level two (building knowledge and confidence) compared to twelve per cent (N=12) of those resident in rural areas. Fifty three per cent (N=51) of rural respondents and fifty three per cent (N=61) of urban respondents were level three (taking action). Full rural-urban comparison between the levels of activation can be found in Figure 5.3.

Figure 5.3 Level of Patient Activation: Rural-Urban Comparison



For the participants' overall activation score, rural respondents (63.31±13.66) were more activated than those in urban areas (59.59±12.75) although this was not significant at $p<0.01$. Therefore, in response to RQ2 rural respondents have a greater level of knowledge, skills and confidence to manage their health compared to urban respondents although this is not statistically significant. Subsequently, the second null hypothesis that stated that '*there is no difference in patient activation in people affected by cancer from rural and urban areas*' can be accepted. Results from the Independent Samples *t* Test are reported in Table 5.15.

Table 5.15 PAM-13: Rural-Urban Comparison

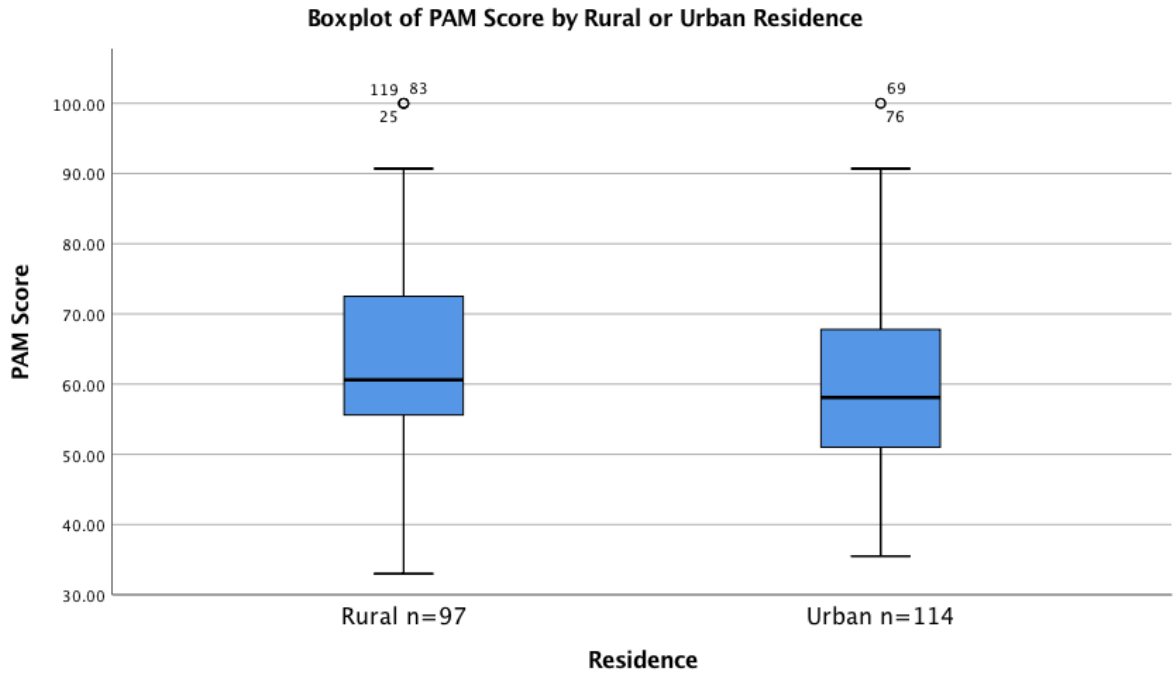
Residence	Mean (SD)	Median	Range	*N*=
Rural	63.31 (13.66)	60.60	33.00-100.00	97
Urban	59.59 (12.75)	58.10	35.50-100.00	114
T value	2.042			
MD	3.72			
95% CI	0.13, 7.30			

Independent Samples –Tests were conducted. Findings were not significant at p<0.01
MD denotes the mean difference between groups. 95% CI represents the 95 % Confidence Interval.

Finally, the comparison of PAM-13 scores can further be compared through a boxplot diagram (see Figure 5.4) that visualises the spread of scores, as well as, the outliers. Whilst both groups had a similar overall range, the median value was greater for rural (60.80) compared to urban

(58.10). Half the scores of each respective group being greater than or equal to this median value and the other half of scores are less. Furthermore, rural participants had a higher interquartile range when it came to PAM-13 scores.

Figure 5.4 Box-plot Comparing PAM-13 by Rural-Urban Residence



5.10.5 CSSES

In relation to RQ3, the mean score on the Self-Efficacy for Managing Chronic Disease 6 Item Scale was significantly (*p<0.01)* greater for rural respondents (7.69±1.84) compared to urban (6.85±2.11). Additionally, rural respondents (7.86±1.70) had significantly (*p<0.01*) greater cancer-related self-efficacy compared to those in urban areas (7.09±1.96). Consequently, the third null hypothesis that stated that '*there is no difference in cancer-related self-efficacy in people affected by cancer from rural and urban areas'* can be rejected. In terms of confidence to perform specific self-management tasks, mean scores for each individual item were compared between groups in order to identify differences between rural and urban respondents. The results indicated that rural respondents had significantly higher self-efficacy than urban respondents with regard to self-efficacy to manage physical discomfort (*p<0.01)*, emotional distress (*p<0.001)* and to contact their doctor about problems caused by cancer (*p<0.01*). Rural respondents scored higher (*p<0.05*) when it came to managing fatigue, other symptoms or health problems and to deal with problems caused by cancer and its treatment by themselves, although this was not statistically significant at *p<0.01*.

There were no significant differences when it came to confidence to complete different tasks and activities needed to manage health and doing things other than taking medication to reduce how much illness affected the participant's daily life. In relation to behaviours directly linked to cancer, there were no significant differences with regard to accessing information, accessing people for support, and finally, getting support from health and social care professionals. The rural-urban comparison of the mean scores for each individual item on the Cancer Survivors Self-Efficacy Scale are reported in Table 5.16.

Table 5.16 CSSES: Rural-Urban Comparison

How confident are you that you can	**Rural**	***N*=**	**Urban**	***N*=**	***T* value**	**MD**	**95% CI**
1. Keep the fatigue caused by your disease from interfering with the things you want to do?	7.25 (2.39)	99	6.46 (2.61)	112	2.275*	0.79	0.11, 1.47
2. Keep the physical discomfort or pain of your disease from interfering with the things you want to do?	**7.85**** **(2.14)**	99	6.87 (2.55)	112	**2.981****	**0.97**	**0.33, 1.62**
3. Keep the emotional distress caused by your disease from interfering with the things you want to do?	**7.99***** **(2.19)**	101	6.74 (2.57)	115	**3.821*****	**1.25**	**0.61, 1.90**
4. Keep any other symptoms or health problems you have from interfering with the things you want to do?	7.32 (2.42)	102	6.58 (2.49)	115	2.217	0.74	0.08, 1.40
5. Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	7.94 (1.99)	102	7.52 (2.10)	115	1.504	0.42	-0.13, 0.97
6. Do things other than just taking medication to reduce how much your illness affects your everyday life?	7.87 (2.18)	102	7.40 (2.25)	113	1.568	0.47	-0.12, 1.07
7. Access information about your cancer and any effects of the diagnosis and treatment?	8.29 (2.07)	102	7.84 (2.20)	117	1.572	0.46	-0.12, 1.03
8. Access people to help and support you when you have problems caused by cancer and/or cancer treatment?	8.20 (2.31)	103	7.61 (2.36)	117	1.864	0.59	-0.03, 1.21
9. Deal with the problems cancer and/or cancer treatment has caused by yourself?	7.60 (2.30)	102	6.69 (2.61)	116	2.710	0.91	0.25, 1.57
10. Contact your doctor about problems caused by your cancer/treatment?	**8.43**** **(2.18)**	102	7.50 (2.66)	118	**2.808****	**0.93**	**0.28, 1.57**
11. Get support with problems caused by your cancer/treatment from health and/or social care professionals?	7.95 (2.36)	101	7.31 (2.54)	117	1.926	0.64	-0.01, 1.30
Self-Efficacy for Managing Chronic Disease 6 Item Scale (Items 1-6)	**7.69**** **(1.84)**	99	6.85 (2.11)	107	**3.032****	**0.84**	**0.29, 1.38**
Cancer Survivors Self-Efficacy 11 Item Scale (Items 1-11)	**7.86**** **(1.70)**	98	7.09 (1.96)	106	**2.954****	**0.76**	**0.25, 1.27**

*The values are expressed as means (SD), and independent samples t-tests were conducted. **P<0.01, ***P<0.001*
Where Levene's Test for Equality of Variance was significant (p<0.05) the Mann-Whitney U Test was conducted to test for significance between groups (Items 2, 3, 10).
MD denotes the mean difference between groups. 95% CI represents the 95 % Confidence Interval.

5.11 Identifying Confounding Variables and Multivariate Analysis

Whilst the results presented from the Independent Samples *T* test have identified significant differences between rural and urban respondents it is important to check for the effect of any confounding variables to be sure that it is rural-urban residence that is explaining the difference in the outcome variables (HPLP-II; CSSES). Firstly, to identify the effect of any potentially confounding categorical variables on rural-urban residence, Pearson's *r* and Pearson's chi-square (χ^2) test were ran and the results were reported in Table 5.17. At *p<0.01* there were significant associations between, living arrangements (*p=.002*), marital status (*p=.001*) and qualifications (*p=.003*).

Table 5.17 Pearson's *r* and Chi-Square (χ^2): Associations between demographic and categorical variables with rural-urban residence

	Pearson's *r*	χ^2 **test**	**Phi and Cramer's V**
Age N=223*	.033, *p*=.620	-	-
Gender N=223	-	3.589, *p*=.058	0.127, *p*=.058
Ethnic Group N=223	-	5.292, *p*=.032	0.154, *p*=.021
Religion N=218	-	2.134, *p*=.344	0.099, *p*=.344
Living Arrangements N=221	-	**9.768, *p*=.002***	**0.221, *p*=.002***
Marital Status N=222	-	**11.155, *p*=.001***	**0.224, *p*=.001***
Employment Status N=222	-	4.005, *p*=.261	0.134, *p*=.261
Qualifications N=218	-	**11.886, *p*=.003***	**0.233, *p*=.003***
Annual Household Income N=200	-	7.192, *p*=.126	0.190, *p*=.126
Primary Cancer Type N=222	-	10.155, p=.338	0.214, p=.338

*Note: Pearsons r was conducted for age as data were not categorical. χ^2 represents Pearson's Chi-Squared Test for categorical variables. Phi was used for strength of association when comparing two binary variables and Cramer's V when comparing between more than 2x2 categories. *Results significant at p<0.01*

Next, multivariate analysis was conducted on all significant categorical and demographic variables from Table 5.17, as well as, rural-urban residence (Table 5.18). This was used to identify the strength of rural-urban residence on the outcome variables while controlling (reducing the effect of confounding variables) for other independent confounding variables. Given there was a significant relationship identified earlier between self-reported health status and rural-urban residence (*5.10.2 Self-Reported Health Status)* this was also included in a further model (Table 5.19).

Table 5.18 Multiple Linear Model of Predictors of HPLP-II; PAM-13 and CSSES

	HPLP-II				PAM-13				CSSES			
Model 1	**B**	**SE B**	**β**	***p***	**B**	**SE B**	**β**	***p***	**B**	**SE B**	**β**	***p***
Constant	2.236 (2.074, 2.398)	.082	-	.000	57.437 (52..808, 62.065)	6.704	-	.000	7.096 (6.436, 7.757)	.335	-	.000
Living Arr.	-.089 (-.405, .228)	.160	-0.75	.581	2.189 (-6.916, 11.294)	4.617	.062	.636	-.267 (-1.597, 1.062)	.674	-.054	.692
Marital Status	.279 (-.012, .570)	.147	.262	.060	.355 (-7.897, 8.606)	4.185	.011	.933	.369 (-.839, 1.577)	.613	.082	.547
Qualifications	**.199 (.057, .341)**	**.072**	**.209**	**.006**	1.761 (-2.174, 5.695)	1.995	.063	.379	.004 (-.560, .567)	.286	.001	.990
Rural-Urban	**.208 (.068, .347)**	**.071**	**.227**	**.004**	2.664 (-1.128, 6.456)	1.923	.100	.167	.677 (.137, 1.218)	.274	.181	.014
R_2		0.19				.024				0.04		
Adjusted R_2		0.17				.005				0.02		

Figures in brackets refer to 95% Confidence Intervals. Values in bold indicate significant association (p<0.01) in multivariable linear regression.
Outcome variables: HPLP rated 1-4; PAM-13 rated 0-100; CSSES rated 1-10.
Dummy variables coding: Living Arrangement (0=Live Alone; 1=Partner/Spouse/Family/Friends), Marital Status (0=Widowed/Single/Divorced; 1=Married/Civil Partnership), Qualifications (0=Lower than degree; 1=Degree or higher), Rural-Urban (0=Urban, 1=Rural)

Table 5.19 Multiple Linear Model of Predictors of HPLP-II; PAM-13; CSSES including Self-Reported Health Status

	HPLP-II				PAM-13				CSSES			
Model 2	**B**	**SE B**	**β**	***p***	**B**	**SE B**	**β**	***p***	**B**	**SE B**	**β**	***p***
Constant	2.048 (1.879, 2.216)	.085	-	.000	51.896 (46.887, 56.905)	2.540	-	.000	5.855 (5.227, 6.483)	.318	-	.000
Living Arr.	-.043 (-.338, .251)	.149	-0.37	.772	4.033 (-4.679, 12.745)	4.418	.144	.362	-.023 (-1.153, 1.107)	.573	-.005	.968
Marital Status	.188 (-.085, .460)	.138	.176	.176	-2.145 (-10.081, 5.791)	4.024	-.067	.595	-.156 (-1.189, .877)	.524	-.035	.767
Qualifications	**.196 (.064, .328)**	**.067**	**.206**	**.004**	2.046 (-1.705, 5.797)	1.902	.073	.283	.029 (-.449, .508)	.243	.007	.904
Rural-Urban	.143 (.011, .276)	.067	.156	.034	1.269 (-2.394, 4.931)	1.857	.048	.495	.407 (-.057, .870)	.235	.108	.085
Self-Reported Health Status	**.356 (.214, .497)**	**.072**	**.355**	**.000**	**9.192 (5.253, 13.131)**	**1.997**	**.315**	**.000**	2.206 (1.704, 2.708)	**.254**	**.534**	**.000**
R_2		0.31				.12				0.31		
Adjusted R_2		0.28				.01				0.29		

Figures in brackets refer to 95% Confidence Intervals. Values in bold indicate significant association (p<0.01) in multivariable linear regression.
Outcome variables: HPLP rated 1-4; PAM-13 rated 0-100; CSSES rated 1-10.
Dummy variables coding: Living Arrangement (0=Live Alone; 1=Partner/Spouse/Family/Friends), Marital Status (0=Widowed/Single/Divorced; 1=Married/Civil Partnership), Qualifications (0=Lower than degree; 1=Degree or higher), Rural-Urban (0=Urban, 1=Rural), Self-Reported Health Status (0=Very Poor, Poor and Fair, 1=Good and Very Good)

A multiple linear regression was calculated to predict health-promoting behaviours (HPLP-II), patient activation (PAM-13) and cancer-related self-efficacy (CSSES) based on living arrangement, marital status, qualifications and rural-urban residence (Table 5.18). In this model, both qualifications (*p<.006*) and residence (*p<.004*) were significant predictors of HPLP-II (R^2=.17, F (4, 148) =8.617, p<.000) when controlling for confounders. Again, when controlling for confounding variables, there were no significant predictors of patient activation (R^2=.01, F (4, 199) =1.230, p<.300). Finally, at *p<0.05*, rural-urban residence (*p<.014*) was the only significant predictor of the CSSES when controlling for confounders although this was not significant at *p<0.01* and this model as a whole was not significant at predicting cancer-related self-efficacy (R^2=.02, F (4, 192) =1.842, p<.122).

Following this, a second multiple linear regression model with the same confounding variables and the addition of self-reported health status was conducted (Table 5.19). Qualifications (*p<.004*), and self-reported health status (*p<.000*) were significant predictors of health-promoting behaviours and explained twenty eight per cent of the variance (R^2=.28, F (5, 147) =12.891, p<.000) when controlling for confounding variables. At *p<0.01* rural-urban residence (*p<.034*) was no longer a significant predictor of health-promoting behaviours. Additionally, in this model, when controlling for living arrangement, marital status, qualifications, and rural-urban residence, health status was the only significant predictor of patient activation (*p<.000*) and explained just 1% of the variance (R^2=.01, F (5, 198) =5.319, *p<.000*). Finally, health status in this model was also the only significant predictor of cancer-related self-efficacy (*p<.000*) and explained twenty nine per cent of the variance (R^2=.29, F (5, 191) =17.077, *p<.000*) when controlling for confounding categorical variables.

Therefore, based on the findings from the multivariate analysis, rural-urban residence is not a significant predictor of health-promoting behaviours, patient activation and cancer-related self-efficacy when controlling for confounders and health status. Self-reported health status was a significant predictor across all three outcome measures. This was evident by the increase in the adjusted *r* square value which highlights that the second model (Table 5.19) that includes health status was a better overall predictor when compared to the first model in Table 5.18. The effect of health status was not surprising given the significant relationship identified earlier between self-reported health status and residence where those from rural areas were more likely to report their health as very good and good compared to those in urban areas.

5.12 Conclusion to Chapter

This chapter has reported on the results from the self-completion postal questionnaire that was used to collect information from a sample of people affected by cancer who had been treated by two acute NHS trusts in the East Midlands of England. The questionnaire collected data on demographics, health-promoting behaviours, patient activation, cancer-related self-efficacy and free-text responses regarding further information. The results have highlighted significant differences between rural and urban respondents across all three of the quantitative outcome measures used in this study.

Firstly, in relation to the first research question, rural respondents had significantly greater engagement with health-promoting behaviours compared to urban respondents ($p<0.001$). Therefore, the results have disproved the first null hypothesis that stated that there is no difference in health-promoting behaviours in people affected by cancer from rural and urban areas. In addition, rural participants scored significantly higher than urban participants on the health responsibility ($p<0.01$); nutrition ($p<0.001$); spiritual growth ($p<0.01$); and interpersonal relations ($p<0.001$) subscales. There were no significant differences between rural and urban participants when it came to the stress management subscale. Rural scored higher on physical activity behaviours compared to urban although this was only significant at $p<0.05$ and not $p<0.01$.

Next, the PAM-13 was used to identify and compare patient activation in people affected by cancer from rural and urban settings. In response to the second research question, participants from rural areas had higher patient activation compared to urban respondents suggesting a greater level of knowledge, skills and confidence to manage their health and health care although this was not significant at $p<0.01$. Consequently, these findings have proved the second null hypothesis that stated that there is no difference in patient activation in people affected by cancer from rural and urban areas.

For the third research question, there was a significant difference in cancer-related self-efficacy in people affected by cancer from rural and urban areas. Overall, using the Cancer Survivors Self-Efficacy Scale the findings highlighted that rural respondents had significantly ($p<0.01$) higher self-efficacy to perform self-management behaviours. For that reason, the third null hypothesis that stated that there is no difference in cancer-related self-efficacy in people

affected by cancer from rural and urban areas can be rejected. In addition, the results indicated that rural participants had significantly higher confidence to manage physical discomfort ($p<0.01$), emotional distress ($p<0.001$) and to contact their doctor about problems caused by cancer ($p<0.01$). At $p<0.05$, rural scored higher compared to urban when it came to managing fatigue, other symptoms or health problems and to deal with problems caused by cancer and its treatment by themselves although this was not significant at the chosen level of $p<0.01$.

However, it should be noted that there were a number of behaviours where there were no significant differences between rural and urban respondents, such as confidence to access information, access people for support, and finally, get support from health and social care professionals.

The fourth research question sought to understand if there was a relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy. The bivariate analysis revealed that there was a relationship between all three outcome measures when compared with one another meaning that the fourth null hypothesis that stated that there is no relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy could be rejected. Firstly, the findings indicated a moderate positive correlation (r=.548) between HPLP-II and the PAM 13 which was statistically significant ($p<0.01$). Additionally, the HPLP-II was positively correlated (r=.466) with the Cancer Survivors Self-Efficacy Scale and this was also significant ($p<0.01$). Finally, there was a significant ($p<0.01$) moderate positive association (r=.483) between the PAM-13 and the Cancer Survivors Self-Efficacy Scale.

Whilst self-reported health status was not one of the primary outcome measures under investigation, it had considerable implications when included in the multivariate analysis. The multivariate analysis went beyond the initial research questions posed at the beginning of this thesis and sought to understand if rural-urban residence was a good predictor of the three outcome variables (HPLP-II; PAM-13; CSSES) whilst controlling for confounders, including self-reported health status. The findings highlighted that rural-urban residence was not a significant predictor of health-promoting behaviours, patient activation or cancer-related self-efficacy when adjusting for living arrangement, marital status, qualifications and self-reported health status. Self-reported health status proved to be a significant predictor on all three outcomes when controlling for confounders. The adjusted r squared value increased

substantially when self-reported health status was entered into the model indicating its much greater effect on the outcomes than residency with regard to health behaviours (0.17-0.28) and cancer-related self-efficacy (0.02-0.29). However, for the PAM-13, health status was a significant predictor, but the model was deemed an extremely poor fit with an adjusted *r* squared of .01.

The above findings are interpreted in the discussion section of this thesis (see Chapter 7). The subsequent chapter presents the results from the qualitative interviews that aimed to identify, explore and compare the barriers and facilitators to self-management in a sample (N=34) of respondents that were recruited from the above questionnaire data (see Chapter 6).

CHAPTER SIX: INTERVIEW RESULTS

6.1 Introduction to Chapter

This chapter reports on the results from thirty four qualitative interviews, conducted from 31st October 2017 to 4th July 2018. Twenty five interviews were conducted face-to-face and nine via telephone and they ranged from approximately 30 to 100 minutes. The discussions were steered by a topic guide, the development of which is detailed in Chapter 4 (4.8.3. Qualitative Data Collection). Data were analysed thematically utilising Braun and Clarke's (2006) approach to thematic analysis, as described in Chapter 4 (4.8.4 Qualitative Data Analysis). When reporting the qualitative results the use of numbers was avoided and the rationale behind this was presented in Chapter 4 (4.9. Reporting the Qualitative Results).

The research questions answered in this chapter are:

- Research Question 5: What are the barriers and facilitators to self-management in people affected by cancer?
- Research Question 6: Do the barriers and facilitators to self-management differ in rural and urban areas?

6.2 Characteristics of Interview Participants

A total of thirty four participants took part in an interview giving a response rate of thirty per cent. The mean age was 63.88 years ± 11.19 (range 39-85), fifty six per cent (N=19) of whom were female and forty four per cent (N=15) male. Seventy four per cent (N=25) lived with a partner/spouse, family or friends and sixty five per cent (N=22) reported that they were married. For self-reported health status, over half (N=18) of the participants said that their health in general was good. There was a good split in geography with forty seven per cent (N=16) being from rural areas and fifty three per cent (N=18) from urban areas. It should be noted that two of the participants (QUAL27 and QUAL32) had experienced cancer recurrence and had subsequently recommenced treatment at the time of interview. Whilst these participants no longer met the initial Participant Eligibility Criteria (see Chapter 4: Table 4.1) it was felt that they still had important experiences to share in relation to self-management

following treatment, as well as, giving them an opportunity to share their story which might not have been possible otherwise. Therefore, their data were utilised in the analysis. Full demographic data for the qualitative sample is reported on below in Table 6.1.

Table 6.1 Demographic Characteristics of Interview Participants

	All respondents *N*=34	***n* (%)***
Age	25-44	2 (5.9)
	45-54	5 (14.7)
	55-64	9 (26.5)
	65-74	14 (41.2)
	Over 75	4 (11.8)
Gender	Female	19 (55.9)
	Male	15 (44.1)
	Other gender identity	0 (0)
Ethnicity	White British	34 (100)
Religion	Christian	25 (73.5)
	No religion	7 (20.6)
	Any other religion	1 (2.9)
Living arrangements	Partner/Spouse/Family/Friends	25 (73.5)
	Alone	9 (26.5)
Marital status	Married	22 (64.7)
	Living with partner	1 (2.9)
	Widowed	5 (14.7)
	Single	3 (8.8)
	Divorced/Separated	3 (8.8)
Employment status	Employed	14 (41.2)
	Retired	20 (58.8)
Qualifications	Degree or Higher	20 (58.8)
	Less than Degree	13 (38.2)
Annual household income	£0-14,999	5 (14.7)
	£15-24,999	9 (26.5)
	£25-49,999	13 (38.2)
	£50-74,999	1 (2.9)
	Over £75,000	3 (8.8)
Residence	Rural	16 (47.1)
	Urban	18 (52.9)
County	Leicestershire	16 (47.1)
	Lincolnshire	12 (35.3)
	Nottinghamshire	2 (5.9)
	Rutland	1 (2.9)
	Derbyshire	1 (2.9)
	Northamptonshire	1 (2.9)
	Staffordshire	1 (2.9)
Self-Reported Health Status	Very Good	9 (26.5)
	Good	18 (52.9)
	Fair	7 (20.6)
Primary Cancer Type	Breast	10 (29.4)
	Urological	6 (17.6)
	Lower Gastrointestinal	5 (14.7)
	Skin	4 (11.8)
	Head and Neck	3 (8.8)
	Upper Gastrointestinal	3 (8.8)
	Gynaecological	2 (5.9)
	Haematological	1 (2.9)

**Percentages may not total 100% due to missing values.*

6.3 Rural-Urban Classifications

In relation to the specific ONS RUC2011 rural-urban classifications, fifty three per cent (N=18) of interviewees lived in an urban city / town (C1), eighteen per cent (N=6) lived in a rural town

/ fringe (D1) and eighteen per cent (N=6) in a rural village (E1). Nine per cent (N=3) of the participants lived in a rural hamlet and isolated dwelling (F1) and only one lived in a rural village in a sparse setting (F2). The rural-urban classifications of the participants are reported in Table 6.2.

Table 6.2 Rural-Urban Classifications of Interview Participants

Classifications*	***n* (%)**
C1: Urban city and town	18 (52.9)
Total Urban (n=18)	
D1: Rural town and fringe	6 (17.6)
E1: Rural village	6 (17.6)
E2: Rural village in a sparse setting	1 (2.9)
F1: Rural hamlet and isolated dwellings	3 (8.8)
Total Rural (n=16)	

**UK Office for National Statistics (ONS) RUC2011 Rural Urban Classifications*

6.4 Barriers to Self-Management

With regard to barriers that prevented participants from engaging with self-management, there were three themes: (1) Location (2) Relationship Based and (3) Personal.

6.4.1. Location

The location of participants often acted as a barrier to engagement with self-management support and this was particularly prevalent with some of the rural participants. Participants identified a lack of tailored and specific support that could potentially have supported them with their recovery from cancer. Firstly, distance proved a factor, in that some participants did not have easy access to bespoke support groups and did not wish to travel too far to attend a group, as well as being faced with heavy traffic. For example the following rural female participant explains:

"I think Maggie's [drop in Cancer Support Centre] said there was a support group there but it is just too far to go every week to Nottingham at that time of day, the traffic is pants, and fitting it in your schedule, so I think there is a gap in the market for something like that" [QUAL06, Female, 39, Gynaecological Cancer, Resident in a Rural Village in Nottinghamshire].

Another urban participant who volunteered in the local hospital and was actively involved with running a support group in Leicester City Centre explained how there was little on offer for those who lived out with the city and surrounding area and that they should not be expected to travel such a long distance for a meeting that lasts only a few hours. He said:

"The difficult thing we found is getting access to those patients. I can do it dead easy to get access to patients, explain about support groups, and they come along; but it is not many. We meet in Leicester, and people come to us from Lincoln: chap who used to work with me. I can't ask him to come across all the way from Lincoln to a support group that lasts two or three hours. Most people don't live in Leicester; or if they live outside it, it's still a struggle to get in. The challenge is to get access to those people and help to get access is not there' [QUAL 16, Male, 74, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire].

The same participant went on to say how it is difficult to reach and deliver emotional support to those from rural areas, he explained, '*some of the support groups are run by the nurses. It is easy to get the people who live locally into the support groups, so they can be helped mentally and emotionally. It is the people in the sticks'* [QUAL16 Male, 74, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire]. Another participant from a rural part of Derbyshire recalls how she could not find any support groups in her local area, she said, '*Umm, I think did have a brief look I don't remember it very much now, I did have a brief look but I couldn't find anything no, that I thought was suitable in this area, in fact I am pretty certain there is nothing here at all'* [QUAL19, Female, 55, Breast Cancer, Rural Village in Derbyshire]. Again, a further participant from a rural part of Rutland when discussing support groups explained how there was not '*anything around here, it was in Leicester'* [QUAL25, Female, 68, Head and Neck Cancer, Rural Town and Fringe in Rutland] and this detracted them from engaging with support groups.

A retired male participant who lived in a particularly rural part of Lincolnshire felt that support for men in his area was lacking. He reported:

"…I made enquires with Macmillan and the GP because support for men, is pretty dire, pretty dire. I knew from the lady who used to come and change my RIG, she was not a Macmillan person. I knew that there were over forty between here and Peterborough with

similar conditions to me, at various stages. But there is nothing, nothing at all" [QUAL12 Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwellings in Lincolnshire].

The same participant went on to say that he felt that there is a lot of emphasis on women and cancer and that men do not tend to talk about their cancer experiences in the same way. He believed that there should be more opportunities for men to share their experiences and that support should be divided by gender where appropriate. He personally would like to be proactive in delivering support to men affected by cancer either through a 'Men in Sheds' type initiative, or as a facilitator on a self-management course such as HOPE, however, he did not feel the mindfulness aspect was for him. He stated:

"I could have seen myself, in that role, as a facilitator, in that kind of group for men, but not doing the mindfulness bit! [laughs]" [QUAL12 Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwelling in Lincolnshire].

6.4.2 Relationship Based Barriers

There were a number of relationships that participants felt were not supportive when it came to their cancer journey, recovery and ability to self-manage. These relationship based barriers are reported on as two sub-themes: (1) Health Professionals (2) Family and Friends

6.4.2.1 Health Professionals

Several participants reported having a negative relationship with specific health professionals and consistently referred back to these negative encounters throughout the duration of the interviews. Notably, participants had "difficulty" with some of their consultants. One participant explained that there were a *'couple that I have had trouble with'* [QUAL12, Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwellings in Lincolnshire] and that he felt patronised and talked down to when discussing his treatment. Another participant who felt they had to be proactive by ringing the hospital *'practically every day'* due to poor communication amongst all levels of staff described the manner of their first consultant as *'appalling'* [QUAL25, Female, 68, Head and Neck Cancer, Rural Town and Fringe in Rutland]. The following respondent described their assigned consultant who was due to perform breast reconstruction surgery as *'very cold'* with a *'horrible attitude'* and that they were *'not coming near me!'* [QUAL09, Female, 57, Breast Cancer, Urban City and Town in Staffordshire]. A further respondent recalled how they did not feel well informed about the

medical side of their treatment and reported that their oncologist did not involve them with decisions regarding their care, they stated:

"I certainly wasn't involved in any discussion about my options. It was just – We are going to do this and this. I was never asked what I think" [QUAL18, Female, 64, Breast Cancer, Rural Town and Fringe in Leicestershire].

A further female participant felt that older people were sometimes discriminated against when it came to conversing with health professionals regarding support. They maintained that age could be perceived negatively and would act as a barrier for how a health professional would offer support in relation to self-management, they reported:

"…they should talk through the whys and wherefores of looking after yourself…you get people who think because of the age you are, you can't do this or that automatically, and this isn't so…" [QUAL21, Female, 85, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire].

6.4.2.2 Family and Friends

Other participants reported the strain that cancer had taken on their close personal relationships and the subsequent psychological impact of this. In some cases, participants reported difficulty as well as, an unwillingness to share their feelings with close friends and family. One participant recalled at the time of interview to the interviewer, *'I don't think we [family] have ever had a conversation like we are having now'* [QUAL12, Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwellings in Lincolnshire]. Others chose to keep their family in the dark and admitted to *'playing it down'* with regard to their cancer as they did not want to overburden their family [QUAL14, Female, 71, Breast Cancer, Urban City and Town in Nottinghamshire]. Additionally, there were participants who cared for older family members whilst undergoing treatment and recovering from cancer, in some cases, parents who had Alzheimer's and Dementia, as well as, caring for teenage children. The time pressures of having dependents with significant care needs could sometimes act as barriers to self-management and engagement with health behaviours.

For one participant, traumatic consequences from treatment altered their future life plans to start a family. They explained below how they were not able to have children following

treatment and how this was a really difficult time for both her and her husband to psychologically adjust, and that it took almost two years to come to terms with:

"I think we struggled, when I was struggling mentally with the child thing. So I had to sort of had to go through a grieving phase which he didn't understand, cause he had already kind of done that, I hadn't cause I was going through cancer treatment so I was focused on that and then when I finished cancer treatment I was like, oh, I can't have kids, my friends were having babies, you feel like they are all around you. So we struggled then because he couldn't see my perspective, so it was trying to get us onto the same page, which we are now. But it has taken two years, so it's just not easy." [QUAL06, Female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire].

Cancer put significant strain on the relationships of some respondents where they completely broke down. This had significant implications for their engagement with self-management and recovery. For example, the following participant explained how their long-term relationship ended as a result of their experiences with cancer. At the time, their ex-partner was abusing alcohol and that interfered with their ability to cope themselves, as well as, providing for two teenage children, they said:

"…as a result of all of this breast cancer treatment, my relationship with my partner fell apart so I had to move… I suppose it was, directly/indirectly, was as a result of the breast cancer … [long pause] and you know you are there trying to support, in a nutshell, my partner just coped with alcohol and then I had the problems associated with all of that, and that overtook what I was dealing with and trying to manage him and then support two teenagers, so…" [QUAL20, Female, 50, Breast Cancer, Urban City and Town in Leicestershire].

Another participant explained how they cared for their husband when he had cancer but when she was diagnosed he was not there to support her and consequently, their relationship broke down, which she was still struggling to come to terms with at the time of interview, they said:

"…obviously the relationship broke down as well from 16 years, that is really hard because it is like I never really mattered, because he had testicular cancer first and that had spread and I just…my kids were still at school and the other two and I did everything [long

pause] absolutely everything you know, cleaned him up when he is sick which is awful, you know I was there and when I had mine he wasn't..." [QUAL23, Female, 45, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire].

6.4.3 Personal Barriers

Within personal barriers to self-management there were two subthemes: (1) Motivational and (2) Emotional barriers.

6.4.3.1 Motivational barriers

The majority of participants acknowledged that engaging with health-promoting behaviours such as physical activity and adhering to a healthy diet were good for them. Many felt that their current level of exercise or diet was inadequate and that they *'could certainly do more'* [QUAL18, Female, 64, Breast Cancer, Rural Town and Fringe in Leicestershire] but *'trying to find the time'* [QUAL23, Female, 45, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire] with other lifestyle commitments often hindered this. Participants did not always contextualise this in relation to cancer and some just felt that they did not exercise or eat as healthily as they did in the past. Whilst some participants engaged with behaviours in the short to medium term, maintaining these in the long term proved more difficult with some maintaining that they would like to return to previous periods in their life where they were 'healthier' or 'fitter'. One participant explained that *'the cancer doesn't stop me, just the normal battle with yourself to maybe do a bit more exercise'* [QUAL33 Male, 67, Skin Cancer, Urban City and Town in Leicestershire]. Admittedly, for a number of respondents, this was down to self-motivation, which participants reported lacking, as well as, feelings of laziness, not having the time, work commitments, older age, and managing other co-morbid conditions.

However, for some, knowing how to engage with healthy behaviours and sustaining them in the long term was more problematic and their lack of motivation was directly influenced by negative experiences of cancer care and/or complications from treatment. For example, the following participant who had completed active treatment for breast cancer had to give up full time work due to their worsening health and was subsequently suffering from a range of physical and mental side effects such as depression and anxiety. They explained below that they did not feel ready to change their behaviour, and could not see any positives to doing so at present, they stated:

"Well I don't think it is the information because I am quite informed about what I should be eating and should be exercising, I am quite up on all of that, it's just motivation to do it, I can't be bothered, and I just can't see the point in doing that." [QUAL34, Female, 49, Breast Cancer, Urban City and Town in Leicestershire].

However, regardless of motivation, some participants, were either reluctant or admitted to not asking for help and maintained that they just *'got on with it'*, one participant in particular acknowledged that they *'couldn't be helped, because they didn't ask for help'* [QUAL19 Female, 55, Breast Cancer, Rural Village in Derbyshire]. For some, they possessed a proactive and 'can do' attitude to their illness whilst others did not seek help because they felt there were no appropriate services in their area that would benefit them.

6.4.3.2 Emotional barriers

A number of participants reported significant emotional and psychological distress as a direct result of their cancer experience and there were respondents who were on antidepressants and referred to a Psycho-Oncology service. Depression and anxiety were common in both the short and longer-term with some of the participants. Consequently, this limited the extent to which they could actively engage with self-management and health behaviours. Whilst the completion of treatment was often perceived as a positive time, some participants described this as a time when they felt very emotional and isolated. For example, the participant below recalled how the completion of treatment was a particularly difficult time where they became depressed. They said:

"You are sent away, stepping off a cliff, and you hope the parachute will open. That was difficult and I became rather depressed" [QUAL17 Male, 68, Upper Gastrointestinal Cancer, Urban City and Town in Leicestershire].

Participants reported a range of side effects from treatment and medication that would often interfere with their ability to effectively self-manage e.g. fatigue, constipation, nausea, incontinence, weight loss/gain, loss of feeling in body parts and hair loss. However, the consequences of treatment went far beyond medical and physiological side effects with respondents having to adjust and come to terms with substantial alterations to their daily lives.

Whilst many of the medical side effects subsided or were reduced in the short to medium term it was often the psychological or emotional effects of cancer that persisted in the long term.

Notably, cancer recurrence was a salient concern in the majority of interviews. For example, the following participant explained how they got anxious in the lead up to follow up appointments in case their cancer had returned, *'I sort of go into myself a little bit. But, you know, it's a pretty scary thought, you are going to be re-diagnosed or whatever. You come out feeling elated when they say, you are all clear!'* [QUAL12 Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwellings in Lincolnshire]. Others explained that they would *'get really obsessed when they have finished treatment, obsessed about it coming back, every ache and pain, is that cancer?!'* [QUAL06 Female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire]. Another participant recalled, '*I don't think people that haven't been through it will never appreciate that my life will never be the same again, there isn't a day that goes by where I don't think about it'* [QUAL07 Female, 44, Breast Cancer, Urban City and Town in Lincolnshire]. The respondent below explained how despite the follow up appointments putting their mind at rest, they still worry about recurrence:

"Because cancer is such a silent killer, you can have it for ages before you even know you've got it. By giving you a scan every five years, three years; after, it puts your mind at rest. It worries me the fact that I could be walking about and not know I've got it." [QUAL05 Female, 54, Breast, Urban City and Town in Lincolnshire].

6.5 Facilitators to Self-Management

In relation to facilitators that enhanced participants awareness and active participation in their recovery there were three subthemes from the interview data: (1) Effective Communication and Information; (2) Informal and Peer Support and (3) Motivation.

6.5.1 Effective Communication and Information

The first facilitator to self-management was related to communication, notably, establishing articulate and positive communication with health professionals in order to best maximise knowledge exchange from medical appointments. This was prevalent when participants were undergoing treatment which seemed to have long-term implications for positive self-

management behaviours post-treatment. Furthermore, effective communication was also a salient concern when participants had completed treatment and were in receipt of follow up care. For example, the male participant below explains:

"I suppose the thing that in terms of managing health is to try and be articulate and positive and not thinking, not thinking unreasonably positive about if I am ill not being ill but just to try and communicate really well with people in charge of it" [QUAL10, Male, 53, Skin Cancer, Rural Village in Lincolnshire].

In order to get the most out of communication with health professionals, some participants brought a friend or family member with them who would in some cases ask questions on their behalf or take note of what was being said in case they forgot following the meeting. For example, the participant below brought their son with them to appointments:

"Also, I had my son with me. He spends a lot of time interviewing people for flash jobs. He is in there like a knife" [QUAL21, Female, 85, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire].

Another participant explains how their approach was that they wanted to know as much as possible about their care and situation, therefore, they had a desire to ask questions to best understand their situation which was in contrast to a family member who had passed away from cancer a year earlier, he said:

"Going back to my cousin's husband who lost his battle to colon cancer last year, his approach was very different to mine. He would ask my cousin to go along to all the clinical meetings. He would just say to her – you tell me what I have to do, I don't want to know anything else. That was his stance all the way through. I couldn't have done that: I needed to know. I had this compulsion: I had to ask questions – tell me about this, explain why this and why that" [QUAL17, Male, 68, Upper Gastrointestinal Cancer, Urban City and Town in Leicestershire].

A further male participant from Lincolnshire felt it was important to put thought into the questions that they would ask in advance, as well as, being proactive and developing their own techniques for self-management. They said:

"I think in a way … [pause]… it depends what you ask them. If you ask them a fairly mundane question like the A&E thing you know, 'what is your hours of opening?' 24/7!' but at the same time, no, they were fine. And a lot of it is you have to develop your own techniques to changing and taking care of things" [QUAL11, Male, 73, Lower Gastrointestinal Cancer, Urban City and Town in Lincolnshire].

Some participants would organise their questioning through writing things down, as well as, keeping folders and diaries in relation to their care. One male participant explained how he *'writes things down and goes through them systematically'* [QUAL28, Male, 70, Urological Cancer, Urban City and Town in Leicestershire]. In some cases, participants had methodically kept records of their appointments, made note of telephone numbers for health professionals that they could contact if they had any problems following treatment which acted as a great reassurance even if this was not utilised. Many of the participants had a good relationship with those delivering their care and in some instances, felt they could 'ask anything'. For example, the female participant from Nottinghamshire explains:

"And I knew I could ask anything as well. And I think that is important too that sometimes you feel as if you are asking silly questions but they are never bothered, they just said ask anything, yeah" [QUAL14, Female, 71, Breast Cancer, Urban City and Town in Nottinghamshire].

Whilst some participants wanted to understand every aspect of their care, including the technical aspects that related to treatment, it was also very important for others to have information they could understand that was accessible. Some found this through literature at the hospital whilst others were proactive and used the internet for practical and easy to understand information such as the female participant below:

"I found out a lot of information myself even after having all the operations. I was careful: I only used one particular website; which was a good one; not a scary one. The hospital had recommended it, but it was one I had found for myself. It was practical, good information" [QUAL31, Female, 62, Lower Gastrointestinal, Rural Hamlet and Isolated Dwelling in Leicestershire].

Engagement with different types of information was dependent on the individual. Some, like the participant above, would use the internet on a regular basis whereas others would only use information that was communicated to them from health professionals as they deemed this a more 'credible' source. Others took a combined approach with many acknowledging that they had to be 'careful' when using online websites and forums for information on cancer.

There were several instances where rural and urban participants positively described their relationship with their local GP and this was particularly prevalent within the rural data. For example, participants said their GP was *'phenomenal'* [QUAL12, Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwelling in Lincolnshire] *'very good'* [QUAL26 Male, 76, Urological Cancer, Urban City and Town in Leicestershire] and *'on the ball'* [QUAL29 Female, 70, Upper Gastrointestinal Cancer, Urban City and Town in Leicestershire]. Another participant explained how their GP didn't know much about their cancer but was *'very good'* and *'supportive'* [QUAL01, Male, 70, Urological Cancer, Rural Town and Fringe in Lincolnshire]. One participant from an urban part of Lincolnshire had recently moved but wanted to stay with their existing GP *'because they know I feel more confident because of what I have been through, to stay with the same GP basically'* [QUAL05, Female, 54, Breast, Urban City and Town in Lincolnshire]. In addition, the following female participant explains their positive experiences and familiarity with their local GP practice:

"I love it. I love that I don't worry about saying anything, I don't even have to say my name when I walk in, they know me, and so I really like that, it just feels like it's safe" [QUAL06, Female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire].

6.5.2 Informal and Peer Support

Informal and peer support were primarily delivered via friends, family and other people affected by cancer. This was particularly salient when it came to the emotional management of having been diagnosed and undergone treatment for cancer, which consequently had a knock on effect on ongoing medical management, as well as, engagement with health behaviours.

Firstly, many participants recalled how close friends and family would frequently accompany them to medical appointments which acted as a source of emotional and social support. One participant recalls the support from their family, and in particular their eldest son as *'terrific'* and *'tremendous'* who would take them to the hospital when undergoing treatment [QUAL21,

Female, 85, Lower Gastrointestinal, Urban City and Town in Leicestershire]. There were also instances where participants raised concern for others who perhaps did not have access to private transport and had to rely on public transport, as well as those who had to travel to appointments by themselves. For example, the woman from Leicestershire below stated:

"I think I was very lucky because my husband could always take me to the hospital and take me home; whereas other people on the bus, I don't know how they went on the bus and came home after treatment. I'm lucky I have quite a close family as well" [QUAL18, Female, 64, Breast Cancer, Rural Town and Fringe in Leicestershire].

Several of the participants reported feelings of depression and anxiety and some were on medication such as propranolol, diazepam, and citalopram. For some of these participants, cancer had triggered the onset of depression and anxiety, whilst for others it had exacerbated a pre-existing condition. One participant explains how they felt depressed and lonely following their treatment for cancer *'I became very depressed in 2015 and it was like I didn't want to carry on anymore because everything was going wrong…I was lonely'* [QUAL23, Female, 45, Lower Gastrointestinal, Urban City and Town in Leicestershire]. However, friends and family were a significant source of support in coping with this, as well as, motivating participants to get better. For example, the male participant below who was suffering from depression explains how it took a nurse to point out the effect it was having on his family to motivate him to stop refusing support from his wife and children. He explained:

"Yeah, I got a grip. She was very good about it but she said look what it is doing to your wife, look what it is doing to your kids. They want to help and support you. But if you refuse, it just makes the situation worse. So yeah, I got a grip" [QUAL12, Male, 62, Head and Neck Cancer, Rural Hamlet in Isolated Dwelling in Lincolnshire].

In particular, spouses were a strong source of support and the following male participant explained how it was his wife that 'pushed' him to go see a doctor if anything was wrong whereas otherwise he felt he might not bother, he said *'Umm, mostly when I go, my wife pushes me to go'* [QUAL15, Male, 69, Haematological Cancer, Rural Village in Lincolnshire]. Another female participant recalls how important support from her husband was following her breast surgery. She stated:

"Yeah, my family and support from my husband, he has really been a brick, has his faults, as like all people do, my god, after the operation he was totally unexpecting it, he was absolutely fantastic" [QUAL19, Female, 55, Breast Cancer, Rural Village in Derbyshire].

Some participants had close friends and family members who were health professionals and these facilitated emotional support, as well as, a welcome source of information and insight. For example, the male participant below from a rural part of Leicestershire explains how his daughter who was a nurse supported him in putting cancer behind him:

"My daughter did. She was a big help; being in nursing, she has a lot of insight; to get my mind right to start with it. You get the diagnosis and you start to look for signs. It was quite a while before I turned the corner and pushed it to the background" [QUAL30, Male, 80, Urological Cancer, Rural Village in Leicestershire].

Several participants explained how they had a good level of support from their employers when they needed to take time off. For example, the female participant below explains how her experience with cancer in some ways brought her closer together with her colleagues who were accommodating in her absence. She stated:

"Well it was about for me I had incredible support from family and some friends, my work colleagues, we just work in a small team and they obviously had to fill the gap of my absence and doing extra hours but then they would also come and visit me at home and it really kind of brought us close together and the team and kind of saw them even more as friends not just work colleagues and I learnt to kind of value the time that I had the time off and I knew that it was all about treatment and just getting better and then actually wanting to go back to work" [QUAL20 Female, 50, Breast Cancer, Urban City and Town in Leicestershire].

Another female participant who worked as a teaching assistant and had substantial complications with her treatment and had to undergo several operations explained how she was very well supported by her employer:

"Yes, they have been very very good considering I have probably had more time off in the last 3 years than I have been there, very very good and the first time they paid me up, I think they paid me the first 9 months full and then half, and I went before that stopped and then obviously I wasn't expecting to, I hadn't been back so long when I had the emergency op in the

March and again they paid me full and this last time, this planned one they paid me full as well…they are all fantastic. They have supported me all the way along" [QUAL23, Female, 45, Lower Gastrointestinal, Urban City and Town in Leicestershire].

Participants were asked about engagement in support groups or talking to other people affected by cancer. For some, they *'didn't feel the need. I was lucky, I have a lovely family, very supportive'* [QUAL31, Female, Lower Gastrointestinal, Rural Hamlet and Isolated Dwellings in Leicestershire]. However, even when people have access to support groups within rural communities it cannot be assumed that everyone within that area will want to engage as identified from the respondent from rural Lincolnshire below:

"I actually particularly avoided those because I, uhh, probably in terms of, I thought, it happened, and I don't want to keep reliving it" [QUAL01, Male, 70, Urological Cancer, Rural Town and Fringe in Lincolnshire].

Others said that they did not think they needed to go to any support groups *'but nobody offered it anyway'* [QUAL24, Male, 72, Upper Gastrointestinal Cancer, Urban City and Town in Northamptonshire]. Another participant said, *'I knew they were there, but didn't need them'* [QUAL26, Male, 26, Urological Cancer, Urban City and Town in Leicestershire]. At the same time, several participants benefited greatly from support groups and peer support .The participant below stated:

"Yes, to start with, feeling very sorry for myself, then when I joined these cancer support groups, I met a lot of other patients which helped" [QUAL16, Male, 74, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire].

Moreover, others welcomed the opportunity to talk to people they could relate to. For example, the following participant explains how after they completed treatment it was difficult to share their experiences of cancer with people who had not been through the same thing:

"You come out the other side of it, eventually. It is one of those things, you can't explain to people unless you have experienced yourself" [QUAL25, Female, 68, Head and Neck Cancer, Rural Town and Fringe in Rutland].

Another participant maintained that they could be more open with people outside of their immediate friends and family. They also stated how they would like to start of their own support group given the amount of women who have been affected by breast cancer in the local area:

"You are trying with your family to be brave. You can be more open with somebody that perhaps you don't know. I live in a large village, but there are so many women with breast cancer. We thought we could start a group of our own" [QUAL18, Female, 64 Breast Cancer, Rural Town and Fringe in Leicestershire].

The following participant explained that they supported themselves through supporting others, which was common with other participants who seemed to benefit by getting involved with helping others through initiatives such as volunteering and charity work. For example, they said:

"I have not gone to any support groups because in a way, I have been supporting others, because I am not a shrinking violet, I am not, 'I have got cancer' [said quietly]" [QUAL03, Female, 68, Breast Cancer, Rural Town and Fringe in Lincolnshire].

6.5.3. Motivation

The final facilitator was motivation and there a range of things that motivated participants to engage with self-management and health behaviours such as, adhering to a healthy diet and exercising. For example, some played sports such as golf and tennis with friends, as well as, competitively, and found that these activities were a good source of exercise and relaxation in addition to being a welcome social activity. For example, this male participant said, *'yeah, well umm… there is a physical side obviously of playing golf and so on, but there is also the mental side to it, the company and the friendship, and comradeship'* [QUAL15, Male, 69, Haematological Cancer, Rural Village in Lincolnshire]. For many, participating and belonging to a group often motivated participants to be, and remain both physically and mentally active. Some participants who were particularly active prior to their diagnosis would use this as an incentive to recover and get back to doing something that they thoroughly enjoyed such as the participant below who was a keen cyclist prior to having cancer. He explained:

"I would like to get back to cycling; I need to get back on the exercise bike and do some work on that before I get on the road. It is good to set yourself goals, I think, as part of the self-management thing. It is easy to sit in a chair and become an old boy. I'm not ready for that yet." [QUAL17, Male, 68, Upper Gastrointestinal Cancer, Urban City and Town in Leicestershire]

Some participants had a *'desire to keep fit'* or to *'lose weight'* and acknowledged that taking care of themselves physically also improved their mental health. For example, this female participant reports how her motives for exercise have somewhat changed, she said *'I used to exercise to get fit, stay thin, or whatever, whereas now I do it for entirely different reasons, I do it because it makes me feel good in my head, which I think is really important'* [QUAL06, female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire]. For some, goal setting and healthy competition that came with taking part in activities such as the local 'parkrun' were considerable incentives to keep active, for example the following participant explains their motivations for running, as well as their desire to return to participating in the local 'parkrun' in their area:

"My intention, they are very clever because after fifty runs you get a t-shirt or after one hundred, so there is always something to aim for with them. And as I say the benefits were that I lost weight, I felt good and I need to get back on and do that" [QUAL13, Female, 57, Gynaecological Cancer, Rural Hamlet and Isolated Dwelling in Lincolnshire].

Furthermore, engaging in and benefiting from practices such as yoga, Tai Chi, aerobics, Pilates and meditation were prevalent with several of the interview participants, and were a welcome source of activity, as demonstrated below:

"I do Tai Chi…so that's useful as well for me. But it is relaxing. They say it is meditation with movement really. So it is relaxing I find. And I quite like to have to remember the sequence, it's good for balance as well, so I just find that keeps me relaxed really" [QUAL14, Female, 71, Breast Cancer, Urban City and Town in Nottinghamshire].

Digital apps facilitated engagement with meditation where participants reported utilising apps such as 'Headspace' and 'Buddify'. For example, the participant below explains

how her friend and yoga teacher introduced her to using Headspace and how this has also benefitted her husband. She stated:

"…she and also my yoga teacher, shared an app you can get on your phone, 'Headspace'…..It's great! So you can download it for free and then you get like ten, ten minute sessions, for free and you can decide whether you want to upgrade or not. I have. So I've got my husband on it as well, he is quite stressed at the moment so he is on there, doing that." [QUAL06, Female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire].

Another participant below explains how practicing mindfulness mediation using a digital app was particularly beneficial when they were undergoing treatment and having difficulty sleeping, they said:

"And I used that [Headspace App] and that was invaluable and actually sort of the latter sort of the chemo when they were trying to cannulate and just feeling horrible you could sort of use these techniques of mindfulness. And I have still got this, I don't kind of use it as much now as I have gone back to being too busy but that was incredible, on nights when you just couldn't sleep between treatments and using it at 2 or 3 o'clock in the morning and I would sit and do some mindfulness and kind of having a bath doing the mindfulness" [QUAL20, Female, 50, Breast Cancer, Urban City and Town in Leicestershire].

Other hobbies and activities, that participants reported engaging with and enjoying included painting, reading, making music, craft woodwork, knitting and embroidery and information technology (IT). These often facilitated stress management and relaxation.

For those participants who had grandchildren, they provided a firm incentive to recover and look after themselves following cancer treatment, so they could continue to be involved in their lives. For example, the following participant said '*I think certainly having grand kids, you want to be healthy for as long as possible'* [QUAL22, Male, 58, Skin Cancer, Urban City and Town in Leicestershire]. The female participant below recalled how she did not have much time for physical activity groups locally in the midst of looking after three grandchildren, pets and working, however, they felt that being so busy and having several dependents kept them active. They said:

"No. I look after three grandchildren as well; I don't have time! I just don't have time, with a job and pets and things. I look after the three grandchildren, one that is seven, three and eleven months. So, my two daughters work. So, I have the two eldest all week. I take one to school, I have on here and then I have the youngest one twice a week, so it keeps me fit" [QUAL05, Female, 54, Breast Cancer, Urban City and Town in Lincolnshire].

As mentioned above, pets, notably participants having dogs who were dependent on them was a strong incentive for many of the participants, particularly those from rural areas to engage in walking on a consistent basis. For example, *'Yeah, so I have three dogs, so that is walking for an hour, hour and a half every morning'* [QUAL12, Male, 62, Head and Neck Cancer, Rural Hamlet and Isolated Dwelling in Lincolnshire]. Another participant said, *'we've got the dogs, so we are out and about for walks and things and I suppose especially with the puppy now, we are out more than we are in'* [QUAL02, Female, 58, Head and Neck Cancer, Rural Village in a Sparse Setting in Lincolnshire]. The following female participant recalls how their living area is well suited to walking their dog, *'I've got a dog and I was saying to my friend the other, my whole life I wanted to go somewhere that I could go for a dog walk without having to go into the car, I have that now. We can go for four different types of walks from here which is lovely.'* [QUAL06 Female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire]. A further participant felt the only reason they exercised was because they had a pet, they said, *'I exercise because I've got the dog'* [QUAL05, Female, 54, Breast Cancer, Urban City and Town in Lincolnshire].

More formal sources of support such as utilising the services of a nutritionist, a physio or psycho-oncologist helped to facilitate or in some cases, initiate ambitions of adherence to health behaviours as stated below:

"And I have decided I need to do something so I have, and just last week I have got a nutritionist to sort my diet out for me and she sent me a diet plan yesterday so I am now trying to do something about my weight through my nutrition. And she has tried to do me, she has read up about after care for cancer patients and to fit a diet around that as well" [QUAL34, 49, Female, Breast Cancer, Urban City and Town in Leicestershire].

Additionally, several participants reported that engagement with the UK based weight loss initiative 'Slimming World' was an incentive to try and eat more healthily. For example, this female participant explains, *'when I do have to go and get weighed every week, I do make more of an effort'* [QUAL02, Female, 58, Head and Neck Cancer, Rural Village in a Sparse Setting in Lincolnshire]. Another male participant commented that he did not join Slimming World himself but because his wife was doing it *'by proxy I was doing the diet as well…at the time I was doing most of the cooking'* [QUAL22, Male, 58, Skin Cancer, Urban City and Town in Leicestershire].

For many participants, maintaining a garden was a facilitator to activity. For example, the man below explains how he enjoyed the exercise that gardening offered, as well as, the opportunity to grow and cook his own vegetables. He stated:

"Um [laughter] well certainly I like the enjoy the exercise of it, it is nice to grow things, to grow your own stuff to garden even a simple cabbage, just go cut it or some carrots and just cook it an eat it straight away you know and the flavour seems more intense and so on you know" [QUAL15, Male, 69, Haematological Cancer, Rural Village in Lincolnshire].

Another participant reported that they benefited both physically and mentally from growing things in their greenhouse, they said:

"Yes but it is not just that, I do a lot in the greenhouse. I like to grow seeds and plants. It is good for your mind as well as your body" [QUAL30, Male, 80, Urological Cancer, Rural Village in Leicestershire].

Time proved to be a facilitator to recovery. Several participants recognised that they should not try and do 'too much too soon'. However, for some they would plan short trips or holidays to aim for throughout their recovery and as the time since diagnosis and the completion of treatment went on, this enhanced their positive outlook and motivated them to take care of themselves, as the participant below recalls:

"I'm more motivated now. I don't want to get any fatter. I feel well. I feel like it is two years now; maybe I'm going to be one of the ones who survive a long time. I'm feeling the

longer it goes, the better chance I have. I'm just more positive; want to be healthier" [QUAL33, Male, 67, Skin Cancer, Urban City and Town in Leicestershire].

6.6 Experiences and Preferences of Living Space

A prominent theme from the data was the participants experiences and preferences of their living space, and the idea of 'rural versus urban' or 'urban versus rural' and many of the participants discussed rural living or urban living in contrast to the other. Some participants felt indifferent about the impact of where they live on their health and reported that where they live is *'not a positive or negative really'* [QUAL33, Male, 67, Skin Cancer, Urban City and Town in Leicestershire]. Another woman from a rural part of Leicestershire felt where she lived was *'not detrimental because I'm not in the middle of nowhere, if I needed public transport, I would be able to do so, I don't think it has been a disadvantage'* [QUAL31, Female, 62, Lower Gastrointestinal Cancer, Rural Hamlet and Isolated Dwellings in Leicestershire]. A further participant, originally from Essex, who had moved to a particularly rural part of Lincolnshire felt that it did not matter if you lived in a rural or urban area, they stated *'I just think if your number is up, your number is up, it doesn't matter where you live, you know, you could live in the middle of London and you probably have less chance of getting to a hospital quickly than you do here'* [QUAL02, Female, 58, Head and Neck Cancer, Rural Village in a Sparse Setting in Lincolnshire]. Again, another participant from a rural part of Leicestershire felt somewhat indifferent and felt that their ability to manage their health and take care of themselves was down to their traits as an individual, they explained *'I don't think it has a negative impact, I'd think I'd be the same wherever I lived because of who I am'* [QUAL29, Female, 70, Upper Gastrointestinal Cancer, Urban City and Town in Leicestershire]. Other participants felt that living in an urban area was less problematic when it came to their health as reported by the male respondent from Lincolnshire below:

"I don't regard ourselves as having the same problems as the more rural people in the county" [QUAL11, Male, 73, Lower Gastrointestinal Cancer, Urban City and Town in Lincolnshire].

Additionally, there were several respondents who had moved from rural to urban areas and were motivated by improving their health but also minimising social isolation, as well as, being closer to services as indicated by the participants below:

"Again, too rural, my health. I've got neighbours here, it is more stable. You know, in a cottage, it was quite lonely there, although we loved it…I love where I am now, it's a lovely location, it's a close, the neighbours are lovely and it's nice here, it's quiet but you are nearer to things" [QUAL34, Female, 49, Breast Cancer, Urban City and Town in Leicestershire].

"So really, the reason for my move was social, to be nearer to friends but also to be nearer to transport and shops and things, and a smaller house…it was very rural where I was before, we didn't have a shop or a pub, or public transport at all, you know, nearest transport was about seven miles I suppose. So yes, that was very rural, very nice but a bit isolating" [QUAL14, Female, 71, Breast Cancer, Urban City and Town in Nottinghamshire].

Furthermore, some urban participants felt reassured and benefitted psychologically from having healthcare and other amenities in close proximity to them. For example, the following two male participants who lived near Leicester city centre stated:

"Being this close to the hospital has been a great reassurance. That has a long term psychological impact. Less stress" [QUAL17, Male, 68, Upper Gastrointestinal, Urban City and Town in Leicestershire].

"It would be a concern if I did live in the country and didn't have all these facilities around the corner" [QUAL16, Male 74, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire].

At the same time, there were several people who had lived in large urban areas in the past, but preferred the rural environment to this, and had chosen to live there. For example, the participants below stated:

"If I compared it to where I lived in Leeds I much prefer it, you can get out and about more, I prefer the rural environment…But there is obviously more buses and sports facilities around, probably more things to do, if you wanted to go to a Zumba class or whatever there are probably more facilities to do stuff like that" [QUAL13, Female, 57, Gynaecological Cancer, Rural Hamlet and Isolated Dwelling in Lincolnshire].

"I would also emphasise that the choice of living in a village, having lived in a city, lived in Manchester for twelve years, umm… but after that I was brought up in the countryside of course, in Shropshire, but always preferred the country life and village life umm…you get to know people, if you are in trouble you have always got help there and I just like it, I just like to be able to walk down the street and you stop and you just know everybody and stop and have a five minute conversation" [QUAL15, Male, 69, Haematological Cancer, Rural Village in Lincolnshire].

Others that had experienced both rural and urban living felt that both experiences had benefited them, for instance the following woman who used to live in Manchester but now resides in a rural part of Rutland recalls:

"I love the fact that we were brought up in the city. I think it gives you a different slant on life. People that live here don't understand the social things that have happened and why. It is almost that they are cossetted; living in the countryside. I feel like I have had the best of both worlds." [QUAL25, Female, 68, Head and Neck Cancer, Rural Town and Fringe in Rutland].

Another male participant who was currently living in a town on the outskirts of Leicester City was planning on moving to an area where it was less busy. He stated:

"More shrubbery, less problems with the traffic, parking and the schools, and all the rest of it" [QUAL26, Male, 76, Urological Cancer, Urban City and Town in Leicestershire].

Community support was prevalent in both the rural and urban data, however, this appeared to be somewhat stronger with rural participants. A female participant from a rural part of Lincolnshire explains her area, *'it's a big village, which if you get involved in it, is wonderful, there are lots of clubs, lots of things to do, if that is what you choose to do'* [QUAL03, Female, 68, Breast Cancer, Rural Town and Fringe in Lincolnshire]. They go on to say how there is a supportive network in their village and that people 'keep an eye on one another' which was consistent with some of the other rural interviews. Indeed, people from rural areas were involved in a wide range of activities such as walking groups, pottering, flower clubs, playing board games such as bridge and scrabble, film societies, keep fit classes and regularly attending local pub quizzes. A female participant from a rural part of Rutland explained how she and her

husband were actively involved in the University of the Third Age (U3A) which is a social movement for retired and semi-retired people to continue learning, she said: *'It is a national group and we have six hundred retired members here in Rutland. In that, there are eighty different interest groups. If someone has got an interest in something, we get together and learn from each other, it is a social thing, as well as learning'* [QUAL25, Female, Head and Neck Cancer, Rural Town and Fringe in Rutland]. Participants who actively engaged with the local community often had strong social networks. For example, the man below from a rural part of Leicestershire explains:

"There are no nasty neighbours. We are good friends. We socialise and have quite a few things going on down at the village. They have a film society. It happens once a month and you have a drink and a natter. We are involved with the local church. We have an annual produce show. It is a nice village really" [QUAL30, Male, 80, Urological Cancer, Rural Village in Leicestershire].

In particular, despite an increasingly secular society, involvement with the church and related activities was particularly important as a source of support for many of the participants in both rural and urban areas. Whilst rural and urban participants both reported varying degrees of 'faith' and 'belief', formal engagement with the church tended to be stronger in the rural areas. For many, the church seemed to offer support on both a spiritual level, as well as, a social level. The following participant from an urban part of Leicestershire explained *'I go to church, I think it is very important to keep going socially'* [QUAL21, Female, 85, Lower Gastrointestinal Cancer, Urban City and Town in Leicestershire]. Others liked the 'peace and quiet' that came with attending church and this facilitated relaxation. Some participants who were involved on church committees and related church groups, as well as, charity work explained how this helped to keep them busy and active within the local community. Another male participant from an urban area in Leicestershire who admittedly was not a 'regular' church goer said how he benefitted psychologically from the support of the church, '*My daughter and wife were church goers. I'm not a regular but I go occasionally. They made you feel important. That was a big plus that so many people were caring, it was really humbling'* [QUAL33, Male, Skin Cancer, Urban City and Town in Leicestershire].

However, not all participants from rural areas were involved with the local community and some actively sought a degree of isolation and wanted to be away from densely populated urban environments, as well as, social events. The retired female participant below who prefers to spend time outdoors with their partner explains how they were aware of the many local activities in their area through a social media page but that they would likely still not be interested in engaging with them. She stated:

"We don't engage with it personally. But there is I think, if you wish to, I mean certainly, the village one way, has community things going on. I belong to their Facebook page and I see what's going on and what they are doing and if we so wished we could go to but it doesn't interest us at all. I don't think it would, even though we have got each other. I still don't think either of us would be interested in that, if we ended up on our own." [QUAL08, Female, 57, Skin Cancer, Rural Village in Lincolnshire].

Furthermore, the following participant who worked as a florist had moved to a rural part of Nottinghamshire shortly before she was diagnosed with cancer and found it a nice environment to live in and had made friends in the area. At the same time, she liked to keep a level of distance and privacy when it came to engaging with people in the local village. She explained:

"Yeah I have made quite a few friends here so it is quite nice. Doing the flower things as well is quite nice, you meet a lot of people in the village. So yeah, I feel very much like a villager, which is quite nice. I am not in like the 'inner sanctum of villagers' because that would do my head in but I can certainly walk around and know people and it's nice" [QUAL06, Female, 39, Gynaecological Cancer, Rural Village in Nottinghamshire].

The interviews highlighted instances where participants who lived in urban areas felt that a sense of community was lacking in comparison to what might be available in a rural area. For example, the man below who lived in close proximity to Leicester City Centre and on a busy road stated:

"I would say it goes against establishing a sense of community because people tend to live inside their houses, you rarely see people out walking unless they have a dog, even then you wouldn't know who they were; certainly not the people over the road divided by the river of traffic. So in that sense, there would be much less support from the community, or you being

known. We are on speaking terms with our immediate neighbours on this side of the road; beyond that a nodding acquaintance with a couple of people. That's about it. We have friends in the area within a few miles, but along this stretch of road, there is one former colleague who lives over the road, other than that we don't know anybody, not much community cohesion…if you lived in a village, whether you liked it or not, you'd be known" [QUAL17, Male, 68, Upper Gastrointestinal Cancer, Urban City and Town in Leicestershire].

A further male participant from an urban town on the outskirts of Leicester also felt that where he lived lacked 'community spirit'. He said:

"As populated as a town is, a conversation with a neighbour from my experience, less in the towns than it would be in the country, when you see your neighbour who is half a mile away and you pass time of day with them. When you live in a town, it is more expensive, and rented accommodation changes tenants regularly and you don't get that community spirit. Those days are over. It is still a bit like that here, part of it is everybody jumps in a car and drives everywhere now." [QUAL28, Male, 70, Urological Cancer, Urban City and Town in Leicestershire].

Another participant from Lincolnshire felt that it should not just be assumed that if you were in an urban area that you had *'shops near you, or doctors near you, you still have to get through to the hospital, that sort of thing'* [QUAL08, Female, 57, Skin Cancer, Rural Village in Lincolnshire]. Indeed, regardless of whether participants were from a rural or urban area, there were instances where both reported problems with accessing the hospital when undergoing treatment as well as when receiving follow up care. Notably, hospital car parking was a significant concern and source of stress for many participants at the major hospitals in Lincoln and Leicester. One participant recalled that the hospital was easy to get to but a *'nightmare to park!'* [QUAL05, Female, 54, Breast, Urban City and Town in Lincolnshire]. Participants also reported frustrations with travelling long distances when receiving treatment and again for follow up appointments that would often take *'a matter of minutes'* [QUAL07, Female, 44, Breast Cancer, Urban City and Town in Lincolnshire]. Additionally, others reported the emotional strain of travelling long distances where one man from a very rural part of Lincolnshire recalls that *'I think the other psychological effect at the time was the journey to and from, eighty, ninety miles and the appointments were never consistent, I could have a late afternoon one day and be there for eight o'clock the next morning, that was not great'*

[QUAL12, Male, 62, Head and Neck, Rural Hamlet and Isolated Dwellings in Lincolnshire]. Others reported that it was a *'huge advantage to be close to the centre where I was getting all the treatment'* [QUAL17, Male, 68, Upper Gastrointestinal, Urban City and Town in Leicestershire].

Not surprisingly, those from rural areas had better access to parks and green spaces compared to their urban counterparts and these were often well utilised, as well as, facilitating opportunities for physical activity, notably, walking. Additionally, as previously mentioned, many of the rural participants had dogs and would regularly walk them two to three times a day in their local area. At the same time, the following participant who lived in a rural part of Derbyshire explains how she had high levels of pollution in her area despite living in an aesthetically pleasing village with access to countryside and greenspaces. She stated:

"Uhh [long pause] well that is a good question because you see living here if you like on a macro level, living here is dreadful because we are right in the Midlands and the air pollution here is just horrendous, it is really bad, everybody knows it. Umm, but on the micro level if you like, living here in this village and this house is really great because, it is really a lovely place to live, I am very very lucky all I have got to do is go through my garden and I am on the canal there is a wall, I've got a gate through onto the tow path and I can get my dog and go through the gate and then we are off, we can walk for miles up the tow path, through the fields or round and through the village and all the rest of it, so that is quite relaxing…" [QUAL19, Female, 55, Breast Cancer, Rural Village in Derbyshire].

Some who lived in what were categorised as 'urban' areas also had easy access to parks and greenspaces so this was not simply determined, or accessible to those solely in 'rural' areas. For, some in urban areas, they had parks within walking distance or a few miles drive and enjoyed this scenario as *'it was not rural, but probably the best of both worlds, amenities on your doorstep and countryside on your doorstep'* [QUAL22, Male, 58, Skin, Urban City and Town in Leicestershire]. Again, another participant who resided on the edge of a town in an urban area stated that they were *'literally five minutes from open fields and countryside, the whole array of walks and so umm… that is nice. I suppose that is a nice thing because I am lucky enough to choose where I live and that makes it nice'* [QUAL20, Female, 50, Breast Cancer, Urban City and Town in Leicestershire].

6.7 Rural-Urban Comparison of Barriers and Facilitators

In response to research question six, the barriers and facilitators that have been identified above were prevalent in both the rural and urban setting. However, on further analysis, some aspects belonging to these barriers and facilitators were more explicit in the rural or urban environment. For example, there was a lack of bespoke support in rural areas and participants acknowledged how traveling long distances to urban centres for support groups was problematic. Equally, there were barriers and facilitators that were not necessarily unique to either geography. Notably, when it came to relationship-based barriers, rural and urban both reported negative experiences with some health professionals and the breakdown of personal relationships as a consequence of cancer. Furthermore, lack of motivation to engage with self-management and psychological distress as a consequence of cancer was not necessarily unique to the rural/urban environment. At the same time, motivation to engage with self-management was not unique and both sets of participants were motivated by a desire to be healthy and take part in group activities and sports. Although rural participants did have easier access to greenspaces and community activities which could have enhanced motivation even further. Table 6.3 reports on the comparison of the barriers and facilitators below

Table 6.3 Rural-Urban Comparison of Barriers and Facilitators

	Rural	*Urban*	*Notes*
BARRIERS			
Location	Lack of bespoke support in rural areas were reported as well as the negative impact of long travel distances to access tailored and specific support.	Urban environment perceived as having better access to healthcare, and tailored support for participants.	There was a lack of tailored and specific support in the rural environment. Although it could not always be assumed that urban meant close proximity to healthcare and amenities. Some people chose rural living as they enjoyed the isolated environment and access to greenspaces.
Relationship Based	Rural participants reported negative relationships with consultants and medical staff. There was considerable strain on personal relationships, in some cases complete breakdown. Caring for children and older family members problematic.	Urban participants reported negative relationships with medical staff also. Again, cancer put strain on their personal relationships, in some cases complete breakdown. Caring for children and older family members was also problematic and acted as a barrier to their own self-management. .	Rural and Urban participants both reported negative relationships with health professionals and family/friends which were not supportive to their recovery. This data did not highlight any uniqueness with geography. However, 'community' links and engagement were stronger in rural participants which could support self-management.
Personal	Some rural participants reported that motivation to engage with self-management and health behaviours was lacking. Emotional and psychological distress as a result of cancer prevalent.	Motivation to engage with self-management and health behaviours lacking with some urban participants. Again, emotional and psychological distress as a result of cancer was a salient concern.	Lack of motivation to engage with self-management and psychological distress as a consequence of cancer was not unique to the rural/urban environment.
FACILITATORS			
Effective Communication and Information	Rural participants adopted a proactive attitude about finding credible information in a range of formats. Reports of good communication and relationships with health professionals to support self-management, particularly local GPs.	Urban participants had a proactive attitude about finding good information in a range of formats. Also reports of good communication and relationships with health professionals to support self-management.	Engagement with different types of information dependent on individual preferences as opposed to geography. Rural and urban reported good communication and relationships with their local GPs but this was more prevalent in the rural data.
Informal and Peer Support	Community support and engagement with the local community was stronger in rural data. Informal and peers support was crucial to participants recovery.	Some participants moved to the urban areas to reduce social isolation. Informal and peer support from friends and family was equally important in this setting too.	Informal and Peer Support was important to both sets of participants regardless of geography.
Motivation	Playing team sports and being part of a group were motivators for physical activity. Participants had a desire to keep fit or lose weight which also motivated them. Digital Apps were an incentive to engage with health beahviours. Many rural participants had dogs which acted as a facilitator to engage with physical activity.	Group activities and sports again were motivators for those from urban areas. Motivation was driven again by a desire to be healthy, keep fit and recover from cancer treatment. Digital apps were also used to engage with practices such as meditation.	Motivation tended to be down to the individual and was not directly influenced by the rural/urban environment. However, easy access to greenspaces and community activities in the rural setting might act as a motivator to actively engage with certain health-behaviours, and subsequently self-management.

6.8 Conclusion to Chapter

This chapter has presented the findings from the thirty four qualitative interviews that were conducted with people affected by cancer from 31st October 2017 to 4th July 2018. Given the research question was 'what are the barriers and facilitators to self-management in people affected by cancer' the findings have been thematically analysed and reported on as 'barriers' or 'facilitators' to self-management with sub-themes where appropriate. There were three subthemes relating to barriers: (1) Location (2) Relationship Based Barriers and (3) Personal Based Barriers. With regard to facilitators there were also three themes: (1) Effective Communication and Information (2) Informal and Peer Support and (3) Motivation. Subsequently, experiences and preferences of living space was another theme where participants reported the pros and cons of rural/urban living and this was reported on. Finally, in relation to research question six, the barriers and facilitators were compared between rural and urban participants. The following chapter interprets both the findings reported on in this chapter, as well as, the quantitative results that were presented in the previous chapter. Given that an explanatory sequential mixed methods design was utilised the next chapter aims to integrate both datasets to answer the primary research question.

CHAPTER SEVEN: DISCUSSION

7.1 Introduction to Chapter

This chapter interprets the quantitative and qualitative findings reported in chapters 5 and 6, in relation to the wider academic literature. Given an explanatory sequential mixed methods design was utilised, this chapter integrates findings from both data sets to further explain and understand the quantitative differences identified between rural and urban participants (Chapter 5). Combining the data sets provided richer answers to the primary aim and research question(s), rather than analysing the qualitative and quantitative data in isolation. Importantly, mixed methods designs are dependent on both quantitative and qualitative methods of inquiry (Creswell and Creswell, 2018), including considering how these different methodologies can be combined or integrated. The mixed methods research question answered in this chapter was:

- Research Question 7: How does the qualitative interview data on barriers and facilitators to self-management further explain any quantitative differences identified with rural and urban populations?

7.2 Discussion

Prior to interpreting the findings from the subsequent chapters, it was deemed important to comment on self-management conceptually from a critical perspective. Whilst it has been firmly embedded and promoted within the literature on long-term conditions and cancer care, both in the UK and internationally, where much of the evidence base suggests that engagement with self-management can improve health outcomes, critics such as Glasgow (2012) and Roulstone and Morgan (2009), encourage a level of caution about considering self-management and self-care initiatives as being politically neutral. Instead, they tend to conceptualise these as neoliberal initiatives that are often promoted in times of austerity where the objective is to shift public health responsibility to the private sector, thus creating a healthy and active individual, whose goal is to return to a consumer society. Whilst it is important to keep that in mind, there remains a need for cancer care to include a more person-centred and holistic approach to meet the diverse needs of the increasing number of people who are living with and beyond cancer. Therefore, it is not surprising that support to ‘self-manage’ these

needs, particularly at the end of treatment, has increased where existing healthcare resources and professionals are already operating at full capacity. In the UK, The Cancer Strategy (2015-20) was developed to make progress with cancer prevention, improve survival rates and enhance patient experience, quality of life and support self-management throughout the cancer journey (Independent Cancer Taskforce, 2015). Self-management has remained a common thread within the strategy and other key initiatives that have evolved from it, such as The Recovery Package (NHS England, 2017) and The NHS Long Term Plan (NHS England, 2019). Whilst efforts to define and firmly situate 'self-management' within the framework for cancer care (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010; Foster et al, 2007) should not go unnoticed and warrant applause, it could be argued that we still lack a consistent definition of the term (that is recognisable to professionals and the public), as well as, universal guidance, as to how it is best practiced and applied in both the acute and community setting. Indeed, it is defined in the survivorship and long-term condition literature as an approach that supports engagement and awareness with individuals in their own care, as well as, promoting health and wellbeing, which understandably make it an easy concept for professionals and policy makers to get behind. For participants who are trying to, or being 'told' to 'self-manage', this may prove more problematic in that linguistically, the idea of the 'self' could imply that people are 'on their own' and left to 'get on with it'. This is at odds with the collaborative relationship between the individual and professional that has been identified within the existing literature (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010). Furthermore, some of the qualitative data that were collected in this thesis, reported on peer support from friends and family and community engagement, none of which are individualistic in essence. For researchers, to ask participants about self-management implies that there is mutual understanding of the term. Furthermore, branding of support and resources needs attention, as this could imply that people affected by cancer are being taught to 'get on with it' 'on their own'. Much like the term 'survivor' this may not carry positive connotations related to 'resilience' and people can perceive it to be a negative label that associates them with a difficult time in their life (Surbone et al, 2013). That is not to say that the idea of 'self-management' could not be empowering and impact some people positively although there is no definitive answer as to how the concept sits with the broader cancer population within the UK and internationally. Whilst it was not an objective of this study, future research could benefit from a concept analysis of 'self-management' within a cancer context, much like previous work on the use of the term 'cancer survivor' by Hebdon et al, (2013).

This thesis revealed for the first time that health-promoting behaviours and cancer-related self-efficacy differ amongst rural and urban UK populations who have completed primary cancer treatment. There is a need to understand the cancer survivorship experiences of people from both rural and urban environments, given almost a fifth (11.13 million) of the UK's total population (66.04 million) reside in areas classed as 'rural' (The World Bank, 2017). However, from the outset, it is important to note that these findings offer a snapshot of people's cancer experience within the East Midlands region of England. The sample size (N=227) for the quantitative data means that the extent to which these findings are generalisable to other regions within the UK are limited, and even more so to international populations. Indeed, much of the existing quantitative research that examines rural-urban disparities and cancer has had considerably larger sample sizes (Gunn et al, 2019; Weaver et al, 2012; 2013) which increases their transferability to wider contexts. Nonetheless, a particular strength of this study was its mixed methods design and the qualitative sample (N=34) was considered sufficiently large (Braun and Clarke, 2013; Clarke et al, 2015) to generate rich data on personal experiences of cancer recovery and self-management. For the purist qualitative researcher, face-to-face interviews can be considered the gold standard and most effective tool for data collection (Doody and Noonan, 2013). This research made use of both face-to-face (N=25) and telephone (N=9) interviews to generate qualitative data in relation to participants' experiences of cancer and self-management. Whilst it would have been preferable to conduct all of the interviews face-to-face, so as to maintain methodological cohesion and continuity, it was also deemed important to offer participants a choice that suited their own personal circumstances and preferences. On reflection, in terms of data quality, there were no explicit differences in the length or richness of the face-to-face and telephone interviews, which in this instance supports this approach to accommodating participant preference. Moreover, discussing sensitive issues such as cancer in an interview can prove challenging and has the potential to cause participants and researchers distress and discomfort (Elmir et al, 2011). Therefore, it was important that participants could decide whether to do this face-to-face or via telephone, as some people might find it easier to discuss this in the comfort of their home or via telephone as this affords them a sense of privacy where they might not have felt comfortable inviting a researcher into their home. Regardless of whether the interviews were done remotely or face-to-face it is important to emphasise that interviewing participants about personal and sensitive topics requires skill and special techniques and the richness of the interview data generated is evidence of the researcher's continuing development in this area. The privileged position of the researcher in relation to 'the researched' has been strongly emphasised and continues to be a recurrent point

of discussion within the extant methodology literature (Råheim et al, 2016) and in this study, the researcher felt very grateful to have met the participants and for them to share their personal experiences, some of which they admitted to not even telling their close friends and family. Despite covering some difficult topics, the interview data generated a lot of positive experiences and the participants should be commended for their willingness to give up their time with no reward. For a more thorough account of the researcher's reflexive thoughts, experiences and overall impact throughout the research process, please see the personal reflection in the concluding chapter (see Chapter 8: 8.6 Personal Reflection).

The explanatory sequential mixed methods design is grounded in the idea that equal consideration should be given to both datasets when interpreting the findings. Table 7.1 below reports on a comparison, of the quantitative and qualitative data, with a view to answering the research question posited at the beginning of this chapter. That is, how does the qualitative data account for any of the quantitative differences identified between rural and urban populations. It should be noted that rural participants reported greater engagement with the local community and more formal engagement with the church, as well as positive relationships with their local GP. This could potentially support some of the significant quantitative differences that were identified in relation to health behaviours and self-management. At the same time, the multivariate analysis highlighted that health status was the most significant predictor across the three quantitative outcomes and not rural-urban residence. The qualitative data showed that many of the barriers and facilitators that were identified were not necessarily unique to either setting which warrants further data collection to better understand the effect of geography on self-management. Nonetheless, the quantitative and qualitative results, in isolation, and when combined, challenge some of the negative assumptions around rurality and health including, limited healthcare resources, the need to travel to access healthcare, and physical and emotional isolation (Goins et al, 2005). The results also highlighted aspects of urban and rural living that have the potential to support people affected by cancer, such as community and informal networks. Indeed, the findings within the extant literature are inconsistent in that both positive and negative aspects of rural living have been identified (Reid-Arndt and Cox, 2010; Rogers-Clark, 2002). Nonetheless, the negativity often associated with rurality tends to receive more attention, and as such, the positive experiences of rural residents in this thesis potentially provide a welcome addition to the existing literature.

Table 7.1 Integration of Quantitative and Qualitative Results

Quantitative Findings	*Qualitative Findings*	*Integration of Quant and Qual – How does the Qual explain the Quant?*
HPLP-II - Rural participants (2.69±0.44) scored significantly (*p<0.001*) higher on HPLP-II compared to urban (2.41±0.42). Rural significantly higher on health responsibility (*p<0.01*), nutrition (*p<0.001*), spiritual growth (*p<0.01*) and interpersonal relationships.	**Barriers** (1) Location (2) Relationship Based - (3) Personal **Facilitators** (1) Effective Communication and Information (2) Informal and Peer Support (3) Motivation	Interview data showed that community links and engagement with the local community were stronger in rural areas which could account for some of the significant differences in the quantitative findings. Some people chose rural living as they preferred the isolated environment and access to greenspaces, and this could have enhanced engagement with health behaviours, and self-management, as well as, accounting for better health status with rural participants.
PAM-13 - Rural participants (63.31±13.66) had higher PAM-13 than those in urban areas (59.59±12.75) although this was not significant at *p<0.01*.	**Experiences and Preferences of Living Space** Participants reported both positive and negative experiences of rural/urban living and some felt indifferent about where they live and how it might impact upon their health and self-management.	Qualitative data highlighted that formal engagement with the church was stronger in rural areas which could support some of the quantitative differences highlighted with spiritual growth and interpersonal relationships.
CSSES - Rural respondents (7.86±1.70) had significantly (*p<0.01*) greater CSSES compared to those in urban areas (7.09±1.96). Significant differences (rural higher self-efficacy) on individual items manage physical discomfort (*p<0.01*), manage emotional distress (*p<0.001*), and to contact doctor regarding cancer (*p<0.01*).	**Comparison of Barriers/Facilitators** The barriers and facilitators that were identified were prevalent in both rural/urban areas. However, some were more explicit in the rural/urban environment.	Positive relationships with local GP's were particularly prevalent in the rural interview data, which could account for some of the significant differences, notably on the CSSES.
Health Status - Rural (4.11±0.85) had significantly (*p<0.001*) higher self-reported health status compared to urban (3.65±0.93).		
Multivariate Analysis Multivariate analysis highlighted that rural-urban residence was not a significant predictor of HPLP-II, PAM-13 or CSSES when adjusting for living arrangement, marital status, qualifications and self-reported health status. Health status proved to be a significant predictor on all three outcomes when controlling for confounders.		Multivariate analysis revealed that health status was the most significant predictor, and some of the barriers and facilitators were prevalent in both rural and urban settings, and not necessarily unique to either geography. Further data collection is warranted with more diverse samples in the UK and internationally.

The study was also novel in that it offered insight into self-management, cancer survivorship and residence, with a UK sample, where there is a considerable evidence gap (see Chapter 2). The majority of the literature surrounding cancer recovery and geography comes from North America and Australia (Adams et al, 2017; Gisiger-Camata et al, 2016; Glasser et al, 2013; Lally et al, 2018; Lawler et al, 2011; Loudon et al, 2017; McNulty and Nail, 2015; Purtzer and Hermansen-Kobulnicky, 2013; Stephen et al, 2017). Whilst geographically these areas are significantly larger than the UK and what constitutes as 'rural' here might be very different than in North America or Australia, regardless of how 'rurality' is conceptualised, it has been well documented that the rural environment offers considerable challenges for people affected by cancer (Butow et al, 2012; Harrison et al, 2009). For example, the need to travel long distances for treatment, having limited access to medical care and other health and social care facilities are perhaps the most prevalent within the existing literature (Arcury et al, 2005; Beck et al, 2009; Noyes et al, 2017). At the same time, when active treatment ends, it could be argued that access to medical care, notably acute care, is less of a priority for people affected by cancer who are trying to recover and engage in self-management. Whilst travelling long distances for follow up appointments at an acute centre may prove a considerable stressor, it is at this point that attention needs to turn to a person's environment (urban or rural), and how they can utilise existing resources to facilitate medical, emotional and role management (Corbin and Strauss, 1988; Lorig and Holman, 2003) following cancer treatment. The findings from this study therefore have the potential to initiate debate within the health and social care community academic, practice and policy communities, as well as, informing further research in the field.

7.2.1 Self-Reported Health Status

It is important to highlight that rural respondents had significantly higher self-reported health status compared to their urban counterparts and so it was unsurprising that they reported greater engagement with health-promoting behaviours and higher cancer-related self-efficacy. This was at odds with American research by Weaver et al, (2012) where rural participants were more likely to self-report fair/poor health. However, their sample was considerably larger (N=7804) and those from rural areas had lower levels of education and health insurance compared to their urban counterparts. Whilst the majority of people in this study, reported receiving free cancer care via the NHS, more participants from urban areas reported having no qualifications (N=30) than those in rural areas (N=8) and poorer health in urban areas could be a consequence of lower educational attainment. Indeed, those with fewer formal educational qualifications, might have a diminished sense of control, and consequently be less 'healthy'

(Hahn and Truman, 2015) preventing them from engaging in self-management, which could account for some of the findings.

Whilst health status was not one of the primary outcome variables under investigation, it had considerable implications when included in the multivariate analysis. Momentarily, putting the multivariate analysis to one side, the first set of research questions (RQ1-RQ3) sought to understand if there were significant differences between rural and urban participants on all three quantitative outcome measures (HPLP-II; PAM-13; CSSES). The results from the Independent Samples *t* test and Mann Whitney *U* Test found a significant difference (rural participants scored higher) on two of these measures which consequently meant that the null hypothesis (there is no significant difference in HPLP-II; CSSES in people affected by cancer from rural and urban areas) could be rejected. For the PAM-13, there were no significant differences at $p<0.01$ and as such, the null hypothesis was accepted. However, the multivariate analysis went beyond the initial research questions and sought to understand if rural-urban residence was a good predictor of the three outcome variables (HPLP-II; PAM-13; CSSES) whilst controlling for confounders, including self-reported health status. The multivariate analysis (Chapter 5: 5.11) revealed that rural-urban residence was a significant predictor of health-promoting behaviours, but not patient activation or cancer-related self-efficacy when adjusting for living arrangement, marital status, qualifications and self-reported health status. Self-reported health status proved to be a significant predictor on all three outcomes when controlling for confounding variables. The adjusted *r* squared value increased substantially when self-reported health status was entered into the model indicating its much greater effect on the outcomes than residency with regard to health behaviours (0.17-0.28) and cancer-related self-efficacy (0.02-0.29). However, for the PAM-13, health status was a significant predictor but the model was deemed an extremely poor fit with an adjusted *r* squared of .01.

7.2.2 Health-Promoting Behaviours (HPLP-II)

The HPLP-II was used to collect data on the health-promoting behaviours and overall, as well as, across both urban and rural, participants scored lowest in relation to physical activity. Existing research has emphasised the role of diet and physical activity in supporting cancer recovery (Davies et al, 2011; Stacey et al, 2015) yet the findings suggest that, regardless of rural-urban residency, people still find these behaviours challenging to engage with. Sixty five per cent (N=147) felt that they got exercise whilst doing daily activities, however, forty seven per cent (N=106) reported that they never took part in leisure time physical activities. The

qualitative data highlighted that participants found taking care of dependents such as pets, children and grandchildren kept them physically active to varying degrees. However, they struggled to find the time for more formal 'leisure activities' and for some this was reported as being due to a lack of motivation. Gardening and involvement with social activities such as walking groups, pottering, flower clubs, playing board games (e.g bridge and scrabble), film societies, keep fit classes and regularly attending local pub quizzes were prevalent within the rural data. These offered an opportunity for physical activity, albeit light activity, as well as, a platform to socialise with others. Winters et al, (2006) maintain that a positive aspects of rural living can be gained from activities such as crafts and gardening and access to outdoor recreation, most of these activities are performed with others which can establish strong social and community networks, as well as, rural values of helping others.

Equally, motivation was also a barrier to eating more 'healthily' in the interview data and the quantitative data highlighted that nearly half of respondents (N=110) never or, only sometimes, chose a diet low in fat, saturated fat, or cholesterol. With regard to daily fruit and vegetable intake, thirty eight per cent (N=85) never, or only sometimes, ate 2-4 portions, and thirty per cent (N=68) never, or only sometimes, ate 3-5 portions. For some of the interview participants, utilising the services of a nutritionist who specialised in cancer, or signing up to a weight-loss programme such as Slimming World, supported them to make more positive dietary choices. The role of health behaviours, such as, physical activity and adhering to a healthy diet has received much research attention in cancer survivorship (Davies et al, 2011) where data suggest that lifestyle interventions can counter some of the adverse effects of treatment, prevent recurrence and reduce the risk of comorbid conditions (Jones and Denmark-Wahnefried, 2006; Pekmezi and Denmark-Wahnefried, 2011).

Whilst interview participants acknowledged that behaviours such as exercise and adhering to a healthy diet were good for them, some struggled with sustaining these in the long term and mostly cited the demands of an already busy lifestyle as a reason for this. However, others reported that their lack of, or non-existent motivation to engage with healthy behaviours was directly related to their cancer experience. In particular, negative experiences of care and complications from treatment had persisted into recovery, and these manifested themselves as both medical and emotional side effects. Some people implement positive health behavioural changes to maintain health and prevent recurrence, or to help them to move forward after cancer, whilst others can feel abandoned and do not report an intention to engage in lifestyle

changes (Corbett et al, 2018). Notably, the completion of treatment and into long-term survivorship marks a difficult period of readjustment (Costanzo et al, 2007; Philip and Merluzzi, 2016) where motivation can be lacking. Additionally, people living past cancer, and surviving long-term, experience different health and emotional needs than those recently diagnosed or undergoing acute treatment (Khan et al, 2012) and these can subsequently influence behaviour. Furthermore, it needs to be remembered that some people will view behavioural change as unnecessary or undesirable, and that cancer is somewhat 'out of their control' regardless of any potential benefits of making changes to their lifestyle (Corbett et al, 2018).

Rural participants scored higher than urban participants when it came to physical activity behaviours although this was not statistically significant at $p<0.01$. This was at odds with a recent study in Australia (Gunn et al, 2019) where rural survivors were more likely than urban survivors to be obese and physically inactive. However, this difference disappeared when controlling for socio-economic status which suggests that this could have caused this association (Gunn et al, 2019). In this thesis, the results could be explained by rural respondents having easier access to parks and green spaces that offer opportunities for physical activity (Winters et al, 2006). The qualitative data highlighted instances where participants reported utilising the rural environment for physical activity. At the same time, there were a number of interview participants who lived in an urban area and were also in close proximity to green spaces. This could be a characteristic unique to the East Midlands of England where many of the main urban centres such as Derby, Lincoln, Leicester and Nottingham have countryside that is easily accessible from the city centre.

Overall, participants scored highest on the HPLP-II in relation to interpersonal relations which also came out strongly in the qualitative data where a considerable facilitator to self-management and engagement with healthy-behaviours was through informal and peer support. This was prevalent in both the rural and urban qualitative data. However, active engagement with the local community, in terms of, being part of groups/clubs and activities tended to be stronger with rural participants, and again rural participants scored significantly higher on this subscale than urban participants. Indeed, work by Purtzer and Hermansen-Kobulnicky (2013) stresses the need for reliance on friends and family, as well as, health professionals within the rural environment. Interpersonal relations were vital to learning about cancer, treatment side effects and self-management (Purtzer and Hermansen-Kobulnicky, 2013). This was in contrast

to qualitative research by Lawler et al, (2011) where people affected by cancer in rural Australia reported lacking community support. Qualitative research by Adams et al, (2017) highlighted the importance of social and community support in rural areas for people recovering from cancer. In this study, some of the urban respondents reported that where they lived lacked 'community spirit'. Indeed, returning to the quantitative data, rural participants scored significantly higher when it came to the interpersonal relations subscale and this could have been a result of closer community support as the qualitative data suggests. With regard to some of the individual behaviours on this subscale, forty eight per cent (N=107) reported that they never or only sometimes discussed problems or concerns with people close to them. The interview data would suggest that informal sources of support such as friends and family can motivate people to engage with their recovery and health behaviours. People have a desire to recover not just for themselves but for their family and loved ones too. Nonetheless, some participants reported that they did not like sharing their cancer experience with close friends and family and preferred to talk to others who had been through the same thing and this could also account for these quantitative responses.

Rural participants scored significantly higher than urban participants when it came to the spiritual growth subscale on the HPLP-II. Research by Adams et al, (2017) suggested that spirituality and religion can support coping with cancer in a rural setting. Whilst this subscale was not explicitly related to 'religious' practices, it should be noted that on the whole, similar numbers of rural (77%; N=79) and urban (82%; N=98) participants identified as being 'Christian'. However, it is likely that not all of these were practising Christians and perhaps this was more to do with how they identify as sixty nine per cent (N=149) said that they never or only sometimes 'feel connected to a force greater than themselves.' In the qualitative sample, nearly three quarters identified as 'Christian' (N=25), how many were active church goers cannot however be definitively established. Nonetheless, despite an increasingly secular society, the qualitative data highlighted the importance of the church for both rural and urban participants. This appeared to be a stable institution that offered support on both a spiritual and social level, as well as being a conduit for community involvement. Perhaps in rural areas where there is limited access to specialised support and fewer support groups, the church is filling a void, hence the positive reports in the interview data.

Thinking more broadly around spiritual practices and stress management, engaging with activities such as meditation and yoga were important for the mental wellbeing of interview

participants in both rural and urban areas. Engagement with digital applications (apps) that facilitated mindfulness meditation was also reported. These types of apps could prove beneficial in rural areas where existing research by Lally et el (2018) and Stephen et al, (2017) has found that web-based interventions and online groups can prove a useful facilitator to self-management. Practicing mediation was not as prevalent, in the quantitative data, where only nine per cent (N=21) of participants reported often or routinely practicing relaxation or meditation for 15-20 minutes on a daily basis. Indeed, yoga might prove a useful self-management practice for people affected by cancer, in particular in rural areas, where research by Loudon et al, (2017) reported that wellbeing and body awareness improved with women affected by breast cancer. Attending yoga sessions also provided a source of peer support where the women could share their experiences.

Research by Winters et al, (2006) on self-management in women with chronic conditions suggests that rurality can influence self-management positively via access to peaceful and quiet environments that are perceived as therapeutic and less stressful compared to those in urban areas. In the quantitative data, there were no significant differences between rural and urban participants for stress management behaviours on the HPLP-II. This was surprising in that some of the qualitative interviews revealed that participants from rural areas frequently enjoyed the rural environment in that it was less densely populated and quieter than the urban environment. In particular, some of the interview participants who had previously lived in an urban area reported preferring the slower pace to rural living and being in a less busy environment.

There were specific behaviours on the HPLP-II health responsibility subscale that merit further discussion, particularly relating to self-management and recovery from cancer. Firstly, fifty one per cent of respondents (N=112) said that they never, or only sometimes, question health professionals in order to understand their instructions. The interview data suggested that some participants had negative relationships with health professionals, perhaps influencing the extent to which they feel comfortable questioning them. On the other hand, this could be a result of participants not wanting to feel ‘silly’ or simply being content with their care and not feeling the need to ask questions. In contrast, the interview data also supports instances where people felt they could communicate effectively with those delivering their care and in some cases ‘ask anything’. However, effective self-management is dependent on a collaborative relationship between the patient and the provider (Department of Health, Macmillan Cancer Support and

NHS Improvement, 2010) so it is paramount that participants feel sufficiently comfortable to ask questions. Health professionals, particularly in an acute setting, frequently get criticised for delivering care that is too 'medical' and focused on treatment as opposed to psychosocial needs. The literature suggests that psychosocial care can improve patient outcomes and reduce distress in people diagnosed with cancer (Legg, 2011; Mcmillan et al, 2016). For Legg (2011), psychosocial care is a key component of holistic care that allows the person affected by cancer to seek both informational and emotional support from caregivers to support self-management. In this sample, eighty per cent (N=179) said that they never or only sometimes asked for information from health professionals about how to take good care of themselves. Indeed, in the qualitative data a participant reported that they could not be helped because they did not ask for help. Health professionals in acute care can be trained and equipped with resources and support to signpost people to psychosocial support, however, if patients are not proactive about asking for help then this interaction might not take place. At the same time, some people will find it very difficult to discuss more personal problems or even struggle with admitting that they need help. In addition, forty six per cent (n=101) said that they never or only sometimes inspected their body for physical changes. Given that 'fear of recurrence' was a salient emotional concern in the interview data , people need to be encouraged to be vigilant with regard to regularly checking themselves properly. Only two per cent (N=4) said that they often or routinely attended educational programmes on personal health care. The quantitative data had a good split between rural (N=103) and urban (N=120) participants so the extent to which this is associated with residency and accessibility is questionable.

Notably, the literature highlights that in rural and remote areas, specialist services are not always locally available meaning people often have to travel long distances to access support (Buzza et al, 2011; Smith, 2012; Virani et al, 2011). In the interview data, several participants reported difficulties with accessing support groups in rural areas, as well as, travelling long distances for treatment and follow up care. Conversely, there were reports from urban participants that living in close proximity to amenities offered significant reassurance. Others, who actively chose to live in a rural area, acknowledged that this was a down side but chose rural living for other beneficial reasons such as a close community and access to countryside. Where support groups and events do exists, be they in rural or urban areas, it needs to be remembered that engagement is based on personal preference. Therefore, events and groups might not be sustainable, even when put in rural and remote areas if they are not in line with population need. Finally, rural participants scored significantly higher on the health

responsibility subscale on the HPLP-II. This could be a consequence of long-term rural living where people have had to adapt and be engaged with their health given limited contact with health professionals or conversely this could be influenced by the positive and more personable relationships that rural participants reported having with their local GP.

7.2.3 Patient Activation (PAM-13)

For the participants' overall patient activation score, rural respondents were more 'activated' than those in urban areas. However, this was not significant at $p<0.01$ with a wide confidence interval, therefore, this finding must be interpreted with caution. The multivariate analysis revealed that residency was not a significant predictor of the PAM-13 when adjusting for confounders. So whilst there was a difference between rural and urban areas, more data are needed to ascertain the effect of residency on patient activation.

Leaving the multivariate analysis to the side and focusing on the significant difference with mean scores, there are a number of reasons in the literature that might suggest why rural participants have higher knowledge, skills and confidence, to manage their health. Firstly, work by Davis et al, (1991) found that people from rural areas conceptualised their health in terms of autonomy and self-reliance; they feared problems with or a decline in their health because it could lead to being a burden on others. Consequently, this mindset could act as a motivator to engage with self-management. The literature that has succeeded this maintains that people in rural areas tend to be more stoic with regards to their health (Judd et al, 2006; Kroneman et al, 2010; Larson and Fleishman, 2003; Thomas et al, 2014). In addition, Butow et al, (2012) suggest that rural populations have greater needs, as a result of limited access to resources, which influences a more self-sufficient lifestyle where they become less inclined to ask for support. When compared to urban rural are less likely to report high/very high distress (Gunn et al, 2019). Indeed, 'self-management' and 'self-care' could be traits that rural people indirectly (or directly) develop throughout their life as they learn to live within the parameters of their environment. Put simply, if you live in an area with limited resources, there might be no alternative but to 'self-manage' and be proactive about your health. Indeed, research by Purtzer and Hermansen-Kobulnicky, 2013 found that people affected by cancer in rural areas used 'active' coping strategies as opposed to 'passive' ones. Therefore, skills of adaption, problem solving, resource seeking/utilisation could potentially become normalised behaviours for those in rural areas. However, the literature maintains that self-management is dependent on collaboration with health professionals (Hibbard et al, 2005; 2007), and if people in rural

areas have limited or no access to health professionals, the extent to which it can be thought of as 'self-management' is questionable. Furthermore, just because rural score higher on outcomes in relation to 'self-management' does not necessarily mean that they are 'healthier' just better at self-managing. In this dataset, rural participants did self-report as 'healthier' when compared to urban participants, so that could also account for some of the differences. At present, there are no comparative data utilising the PAM-13 with people affected by cancer in rural and urban areas, and as such, these findings are by no means definitive.

Another reason for why rural participants scored higher could be due to more rural than urban participants reporting being married or co-habiting. Research in Ireland (Thomas et al, 2014) with people affected by head and neck cancer also found that those in rural areas were more likely to be married or co-habiting and these participants reported higher quality of life compared to their urban counterparts. In this thesis, one quarter (N=30) of the urban respondents reported living alone compared to only nine per cent (N=9) of rural respondents. Given the high prevalence of support from partners and friends in the interview data, this could account for some of the differences in patient activation.

McNulty and Nail (2015) found that rural participants advocate for themselves, their diagnosis, survivorship, and for improved health care within their local communities. The advocacy emerged as seeking a second opinion, accessing resources on support, asking questions and seeking answers, as well as, fighting for financial and employment rights. In rural areas, community advocacy involved fundraising, volunteering with survivorship organisations and public speaking about survivorship issues. In this thesis, self-advocacy and community engagement could also influence higher 'activation' in rural respondents. The interview data highlighted instances where rural participants reported the importance of establishing positive and effective communication with health professionals, as well as, being proactive about seeking credible information online regarding their cancer. Research by Gunn et al, (2019) found that those in rural areas were more likely to have trust in their communities when compared to those in urban areas, and in this thesis, rural respondents talked about establishing friendships and 'keeping an eye on one another'. Furthermore, rural respondents showed signs of being proactive about the prospect of establishing support in their local community where there was a void (e.g. support for men; support groups), as well as, helping others through volunteering and charity initiatives.

7.2.4 Cancer-Related Self-Efficacy (CSSES)

The CSSES was utilised to measure self-efficacy to perform self-management behaviours. Much like the PAM-13, there are no comparative data where this has been used with people affected by cancer in rural and urban areas. Nonetheless, research by Foster et al, (2015) used the CSSES with people who had completed primary treatment for cancer in the last twelve months and there were some similarities with their findings and this thesis. Firstly, it should be noted that overall cancer-related self-efficacy was higher in this research indicating that self-efficacy increases in line with the time since treatment has ended. It should be noted that Foster et al's, (2015) sample consisted of 182 respondents who were predominantly female (81%). In this thesis, there was a more even split with regards to gender (52% Female; 48% Male) which also could have increased the overall self-efficacy score. Confidence to manage fatigue was lowest in both studies which highlights how problematic fatigue can be for people affected by cancer even five years after treatment. This was also reported in the interview data as a treatment related side effect that would interfere with participants' ability to self-manage effectively. This has been raised as a self-management concern in rural areas (Gisiger-Camata et al, 2016), as well as, in the wider survivorship literature (Corbett et al, 2016; Koornstra et al, 2014). In this thesis, rural participants scored higher than urban when it came to managing fatigue (although this was not significant at $p<0.01$) and evidence supports that engagement with physical activity can help reduce cancer-related fatigue post-treatment (Cramp and Byron-Daniel, 2012), so consequently, the higher level of engagement from rural participants with physical activity behaviours could have influenced this. Although, it should be noted that quantitative findings in this study, were not significant at $p<0.01$. In the interview data, rural participants reported engaging with walking on a consistent basis, particularly those who had dogs and this has potential to support fatigue management. At the same time, it needs to be acknowledged that for some, fatigue might act as a deterrent to exercise rather than a facilitator. Fatigue is a salient concern for people recovering from cancer regardless of residence, but this data suggest that rural people are better at managing it.

In this study, participants were most confident when it came to accessing information about cancer, and contacting the doctor about problems caused by cancer. This was in line with existing research (Foster et al, 2015; Watson et al, 2016), indicating that people affected by cancer have high self-efficacy when it comes to these behaviours. In this thesis, the high self-efficacy scores on accessing information and support indicate a sample that were confident and proactive with accessing information. In the interviews, engagement with different types of

information was dependent on individual preference, regardless of residence, with some using the internet on a regular basis, and others only utilising information that was communicated to them from health professionals as they felt this was more 'credible'. Others took a combined approach with many acknowledging that they had to be mindful of information that was posted online regarding cancer. Effective communication and information were identified as a facilitator to self-management in the interviews. However, when it came to accessing information about cancer, there were no significant differences between rural and urban respondents. There were instances where both rural and urban participants reported positive relationships with their local GP although, this was more prevalent in rural areas, as well as being statistically significant ($p<0.01$) in the quantitative data where rural were more confident than urban to contact their doctor about cancer.

Furthermore, rural participants had significantly higher self-efficacy when it came to confidence to manage physical discomfort ($p<0.01$) and emotional distress ($p<0.001$). Indeed, this could have been a result of rural populations being more stoical and self-sufficient than their urban counterparts (Butow et al, 2012; Judd et al, 2006; Kroneman et al, 2010; Larson and Fleishman, 2003; Thomas et al, 2014) or less likely to report high/very high distress (Gunn et al, 2019). Turning to the interview data, participants reported suffering from a range of physical and mental side effects, and we know that these are not unique to rural or urban populations. The literature suggests that people with a diagnosis of cancer report more co-morbid conditions and poorer physical and mental health compared to those without cancer (Smith et al, 2008) and they are more likely to suffer from fatigue (Corbett et al, 2016), anxiety (Greer et al, 2011), depression (Pasquinin and Biondi, 2007), as well as, being at an increased risk of developing secondary tumours (Mariotto et al, 2007). Research by Glasser et al, (2013) on the psychosocial needs of people affected by cancer in rural Illinois found that over half were at risk for depression and in this thesis, participants from rural and urban areas reported feelings of depression and anxiety with some on medication such as propranolol, diazepam, and citalopram. In some instances, cancer had triggered the onset of depression and anxiety, whilst for others it had exacerbated a pre-existing condition. However, returning to the quantitative data, rural participants again appeared better at managing emotional distress. This could have been a result of increased informal support from the community and/or partners given more rural respondents were married or co-habiting. At the same time, it is well documented that emotional distress is a common concern following the completion of cancer treatment regardless of geography.

Although the literature suggests that people in rural areas may be more susceptible to this as a result of physical and emotional isolation (Burris and Andrykowski, 2010; Goins et al, 2005; Hewitt et al, 2006). Specifically, 'fear of recurrence' was identified by the majority of interview participants, and was not unique to the rural-urban split. Indeed, this was something that was never far from the participants' minds regardless of whether they were having a positive or negative experience of recovery with one participant saying that 'there isn't a day that doesn't go by that I don't think about it.' Furthermore, the cancer experience had taken a significant toll on the relationships of some of the interview participants where in some cases relationships with their partner broke down, both in the short term and longer term.

Interestingly, whilst rural participants scored higher again, there were no significant differences between rural and urban people when it came to confidence to get support from health and social care professionals and to access support with cancer. This somewhat challenges the literature that maintains that access to support from healthcare providers is challenging in rural and remote areas. However, this tells us little about whether they were 'satisfied' with their care only that they knew where to go to 'access' support. The interview data highlight both positive and negative experiences with healthcare professionals. Specifically, there were negative reports of dealings with consultants where participants called them 'appalling' and 'very cold'.

Foster and Fenlon's (2011) framework for recovery of health and wellbeing posits that environmental factors such as community and social support, as well as, personal factors (illness perception, mental health) will influence self-efficacy which then subsequently influences engagement with self-management. Indeed, if support, and involvement with the community is greater in rural areas, as the interview data suggests, together with suggestions from the literature about the personal traits unique to rural communities (less inclined to ask for help, self-sufficient etc.) then it is perhaps not surprising that they have scored significantly higher on health-promotion and self-management outcomes such as the HPLP-II and CSSES. Indeed, qualitative research by Sav et al, (2015) highlights that self-managing in a rural area requires much of the same lifestyle changes that are necessary in urban areas. However, the uniqueness of rural life and the limited availability of healthcare means that people in rural areas often need higher levels of organisation and planning, as well as, adopting more creative approaches when it comes to self-management. Furthermore, this resulted in high levels of self-reliance as well as looking to immediate family and social networks for support (Sav et al,

2015). Geographic isolation might increase the burden of self-managing a chronic condition, at the same time, it could provide considerable motivation to continue self-managing. People from rural areas often have to work with their environments and within the constraints of what is available to them. Rural activities can be used to replace those that are not available such as walking or running if they do not have access to a gym or fitness centre.

7.3 Conclusion to Chapter

This chapter has interpreted the findings from the quantitative and qualitative data (Chapters 5 and 6) in relation to the pertinent academic literature. It integrated the quantitative and qualitative findings to further explain the quantitative differences that were identified between rural and urban participants. Rural participants scored significantly higher on all quantitative outcomes and it is posited that factors such as increased community engagement and support, active engagement with the church, access to green spaces and finally, some of the traits of rural communities identified in the literature could explain these. However, at present, comparative data are non-existent therefore limited definitive conclusions can be made. It is hoped these findings will instigate further research in the field on residency and self-management in cancer survivorship.

CHAPTER EIGHT: CONCLUSION AND RECOMMENDATIONS

8.1 Introduction to the Chapter

This concluding chapter provides an overview of this doctoral research that utilised a mixed methods design and aimed to investigate and compare self-management in people affected by cancer who were post-treatment from rural and urban settings in England. It provides a series of recommendations for (1) people living with and affected by cancer (2) health and social care professionals (3) commissioners and finally (4) further research, which were drawn explicitly from the quantitative and qualitative findings that were presented in Chapters 5 and 6. In addition, the existing and planned dissemination and research impact work is reported on. A personal reflection on the author's experiences of leading and conducting this research is also provided.

8.2 Summary of the Thesis

Firstly, to reiterate, the primary aim of this thesis was: **To investigate and compare self-management in people affected by cancer following treatment from rural and urban areas.** This was achieved via, (1) a scoping review of the pertinent academic literature (see Chapter 2), (2) the study design (see Chapter 3 and Chapter 4), (3) the collection of quantitative (see Chapter 5) and qualitative data (see Chapter 6) and finally, (4) the interpretation and integration of the quantitative and qualitative data (see Chapter 7).

In addition, the research sought to provide a comprehensive answer to the primary research question: **What are the differences in self-management in people affected by cancer following treatment from rural and urban areas?**

A series of sub-research questions were also formulated (see Chapter 3: 3.2 Research Question(s)) and these warranted the utilisation of both quantitative and qualitative methods whilst still aiming to answer the primary research question identified above.

There were eleven specific research objectives that the research sought to achieve upon study completion. These are reported on below along with their completion status in Table 8.1.

In relation to the data collection, 227 people completed and returned the self-completion questionnaire (27% response rate). Fifty three per cent (N=120) of respondents resided in an urban area and forty five per cent (N=103) lived in a rural area. Participants from rural areas (2.69±0.44) had a significantly greater Health-Promoting Lifestyle Profile ($p<0.001$) compared to those in urban areas (2.41±0.42). Additionally, rural participants scored significantly higher than urban with regard to health responsibility ($p<0.01$); nutrition ($p<0.001$); spiritual growth ($p<0.01$); and interpersonal relationships ($p<0.001$). There were no significant differences at $p<0.01$ between rural and urban participants when it came to physical activity and stress management. In response to RQ1 the results suggested that rural respondents engaged with health-promoting behaviours more than those from urban areas. Therefore, the null hypothesis in relation to this research question could be rejected.

For the participants' overall patient activation score on the PAM-13, rural respondents (63.31±13.66) were more activated than those in urban areas (59.59±12.75) although this was not significant at $p<0.01$. In response to RQ2 rural respondents had a greater level of knowledge, skills and confidence to manage their health compared to urban respondents but this was not statistically significant and as such, the null hypothesis that there were no significant differences between rural and urban participants was accepted.

In relation to RQ3, rural respondents (7.86±1.70) had significantly ($p<0.01$) greater cancer-related self-efficacy compared to those in urban areas (7.09±1.96). Consequently, the null hypothesis that was derived in relation to this research question could be rejected. In terms of confidence to perform specific self-management tasks, rural respondents had higher self-efficacy than urban respondents with regard to self-efficacy to manage fatigue, other symptoms or health problems and to deal with problems caused by cancer by themselves, but it should be noted these individual items were not significant at $p<0.01$. There were significant differences with confidence to manage physical discomfort ($p<0.01$), emotional distress ($p<0.001$), and to contact their doctor about problems caused by cancer ($p<0.01$). There were no significant differences in confidence to complete different tasks and activities needed to manage health and doing things other than taking medication to reduce how much illness affected daily life, accessing information regarding cancer, accessing people for help and support with cancer, and finally, getting support from health and social care professionals.

Table 8.1 Overview of Research Objectives and Completion Status

Objective	Overview	Status
1. To conduct a scoping review of the literature in relation to cancer survivorship, self-management and rural-urban residency	Through the use of Arskey and O'Malley's (2005) five step framework a scoping review was conducted and the results were reported on in Chapter 2: Literature Review.	Complete
2. To identify a range of quantitative outcome measures from the existing literature that can be used to measure self-management in people affected by cancer from rural and urban areas	The following quantitative outcome measures were identified through the existing literature and utilised to collect data via the self-completion questionnaire: HPLP II; PAM-13; CSSES. These outcomes were reported on in Chapter 4: Research Methods and Chapter 5: Questionnaire Results.	Complete
3. To establish a professional network at two NHS Trusts to support and facilitate recruitment of potential participants.	In order to recruit participants a professional network was established at two acute NHS Trusts in the East Midlands of England. This involved liaising with Lead Macmillan Nurses, as well as, Cancer Centre Staff who acted as gatekeepers to the study population. The recruitment process is provided in Chapter 4: Research Methods.	Complete
4. To design and disseminate a questionnaire that collected data on the identified quantitative outcome measures.	A self-completion questionnaire collected data on demographics, health-promoting behaviours, patient activation, cancer-related self-efficacy and free-text information in relation to self-management. The questionnaire was sent out on behalf of the research team via Cancer Centre Staff at two acute NHS Trusts in the East Midlands of England. The design of the questionnaire was reported in Chapter 4: Research Methods (4.7.7 Questionnaire Design).	Complete
5. To establish a Patient and Public Involvement (PPI) group to pilot research materials prior to seeking ethical approval and data collection.	A PPI group was established consisting of five volunteers who were people affected by cancer. The research materials were piloted with them prior to seeking ethical approval. For further detail please see Chapter 4: Research Methods (4.2 Patient and Public Involvement (PPI) in the Research).	Complete
6. To seek and obtain ethical and research governance approval from the appropriate bodies prior to data collection.	Ethical approval was granted from the University of Lincoln, NHS REC, HRA and research governance approval was sought and granted via both acute NHS trusts that were utilised for recruitment. The ethical approval process can be found in Chapter 4: Research Methods (4.3 Applying for Ethical Approval).	Complete
7. To analyse the quantitative data and write up the results in the form of a thesis chapter.	The quantitative data from the self-completion questionnaire were analysed utilising descriptive statistics, independent samples t tests and multivariate analysis. The results were written up and presented in Chapter 5: Questionnaire Results.	Complete
8. To recruit a sample of people affected by cancer from rural and urban areas to take part in a qualitative in-depth interview.	Thirty four people affected by cancer who completed the self-completion questionnaire were recruited to take part in a qualitative in-depth interview. Participants were purposively sampled in order to get a good spread between rural and urban in order to answer the research question. This is reported on in Chapter 4: Research Methods (4.8.2 Recruitment of Participants for the Qualitative Interviews).	Complete
9. To thematically analyse the qualitative interview data and write up the results in the form of a thesis chapter.	The qualitative data were digitally recorded and transcribed verbatim. These were analysed using Braun and Clarke's (2006) approach to thematic analysis and reported on in Chapter 6: Interview Results.	Complete
10. To integrate the quantitative and qualitative findings and write up in the form of a discussion chapter in this thesis.	A mixed methods research question was utilised to emphasise how the qualitative data would enhance our understanding of the quantitative findings. Therefore, the quantitative and qualitative findings were integrated in Chapter 7: Discussion.	Complete
11. To provide a series of recommendations in terms of self-management support in rural and urban areas.	A series of recommendations for (1) people living with and affected by cancer (2) health and social care professionals (3) policy makers and (4) further research were informed from the findings and are reported on in this chapter (Chapter 8: Recommendations and Conclusion).	Complete

The HPLP-II was positively correlated (r=.466) with CSSES ($p<0.01$), suggesting that those who engaged with health promoting behaviours had higher self-efficacy to perform specific self-management activities. Finally, there was a significant ($p<0.01$) moderate positive association (r=.483) between PAM-13 and CSSES, suggesting that more activated patients have greater confidence to manage their health and perform self-management tasks. In response to RQ4, there was a moderate positive relationship between health-promoting behaviours, patient activation and cancer-related self-efficacy when correlated with one another. Once again, the null hypothesis could be rejected.

The findings from the multivariate analysis identified that rural-urban residence was not a significant predictor of health-promoting behaviours, patient activation or cancer-related self-efficacy when adjusting for living arrangement, marital status, qualifications and self-reported health status. Interestingly, self-reported health status was a significant predictor on all three outcomes when controlling for confounding variables. The adjusted r squared value increased considerably when health status was entered into the model indicating its much greater effect on the outcomes compared to rural-urban residency with regard to health behaviours (0.17-0.28) and cancer-related self-efficacy (0.02-0.29). However, for the PAM-13, self-reported health status was a significant predictor, but the model was deemed an extremely poor fit with an adjusted r squared of .01. Further research is warranted with more diverse and larger samples to examine the effect of health status and residency on these outcomes.

The free-text information in the questionnaire was analysed thematically. The primary theme was the concept of respondents “moving on” and building a meaningful life for themselves following diagnosis and treatment. These data offered valuable insight into the self-management experiences of people affected by cancer post-treatment, as well as, highlighting the merit of free-text comments as an additional data source in questionnaires.

Thirty four people took part in a qualitative interview and forty seven per cent (N=16) were from rural areas and fifty three per cent (N=18) were from urban areas. In relation to RQ5, there were three themes relating to barriers to self-management: (1) Location (2) Relationship Based and (3) Personal. There were a number of relationships that participants felt were not supportive when it came to their cancer journey and these were reported on as two subthemes: (1) Health Professionals (2) Family and Friends. Furthermore, personal barriers were categorised into two subthemes: (1) motivational and (2) emotional barriers.

Again, in relation to RQ5, there were three themes with regard to facilitators that enhanced participants awareness and active participation in their recovery: (1) Effective Communication and Information; (2) Informal and Peer Support and (3) Motivation. Finally, a prominent theme in the qualitative data was the participants experiences and preferences of living space where they discussed rural living or urban living in contrast to the other.

The quantitative findings highlighted that people in rural areas were more engaged with health-promoting behaviours and had significantly higher confidence to self-manage compared to those in urban areas. However, in response to RQ6, the qualitative interviews reported on a range of barriers and facilitators that were not always unique to the rural or urban environment. For example, when it came to relationship-based barriers, rural and urban both reported negative experiences with professionals and the breakdown of personal relationships as a consequence of their cancer. Although some components of these barriers and/or facilitators were more prevalent in the rural or urban setting. For example, there was a lack of bespoke support groups in rural areas and participants acknowledged that traveling long distances to urban centres for support was a disadvantage to rural living. Indeed, a rural or urban environment could act as a barrier or facilitator to self-management depending on the individual. People chose rural or urban living for a host of reasons, some of which were directly related to their health and wellbeing, and for others they do not have a choice where they live. The interviews found that informal support positively influenced recovery and self-management. Rural participants tended to be more engaged and active with their local community, as well as having easier access to greenspaces which could have accounted for some of the differences in health behaviours and self-management.

8.3 Limitations

According to Price (2004, p. 66), 'a limitation of a study design or instrument is the systematic bias that the researcher did not (or could not) control and which could inappropriately affect the results.' Conversely, a 'delimitation' is a systematic bias that is intentionally introduced into the design (Price, 2004), for example, a study might collect data with a particular gender, age group or people with a specific cancer type to understand their unique experiences whilst limiting the generalisability of the findings to a wider population. Scholars such as Puhan et al, (2012) strongly encourage researchers to report on all potentially important limitations that could influence the quality and interpretation of the findings that are being reported on as this

serves to benefit the discipline and future research. Importantly, for Puhan et al, (2012) research that identifies salient limitations serves to shape the future research agenda because it informs the design and conduct of future research. With that in mind, the following study limitations were identified and should be considered when interpreting the findings from this thesis.

8.3.1 Limited Medical Variables

Unfortunately, treatment received and time since treatment began could not be reliably recorded from both the acute NHS trusts that were utilised for recruitment. Consequently, this prohibited any analysis in relation to these variables and the quantitative outcomes. It would have been useful to ascertain if self-management differed with participants based on the time since treatment ended, as well as, the type of treatment received. The questionnaire would have benefited from collecting further data on self-reported treatment, time since treatment began/finished and a cancer-specific quality of life measure and/or symptom checklist. These additional data items would have added useful context and enriched the final analysis.

8.3.2 Demographic Characteristics

The study sample was somewhat homogenous particularly in relation to ethnicity where ninety seven per cent reported as White British (N=220). Existing UK research with people affected by cancer found ethnicity to be significantly associated with self-management uptake (Shneerson et al, 2015b) however, in this research, the sample restricted any analysis in relation to this.

8.3.3 Sample Size

A further limitation was that the required sample size of 417 was not reached. This could be a result of nonresponse bias when respondents differ considerably from those who do not respond as is often the case with postal surveys. However, the demographic and geographic data of non-responders was not accessible to the researcher and as such it cannot be said definitively whether non-responders differed significantly from the final sample. Whilst there were discussions at the Project Steering Group around increasing the sample size via further recruitment utilising an online survey designed using Qualtrics software, the two recruiting sites did not routinely collect email addresses and so any additional recruitment efforts could have compromised the overall study design and robustness of the sampling strategy. Furthermore, given the sensitivity of the topic, comments from one of the PPI volunteers and the NHS REC, the reminder letter was deemed inappropriate. Consequently, it was important

to abide by this and so no reminder letter was sent to participants who did not respond. However, the final sample of 227 was still considerably larger than much of the existing qualitative research on survivorship and rurality. Furthermore, the qualitative sample (N=34) was considered sufficiently large (Braun and Clarke, 2013; Clarke et al, 2015) to generate rich data on experiences of cancer recovery and self-management.

8.3.4 Study Setting

These findings offer a snapshot of people's cancer experience within the East Midlands region of England. The sample size (N=227) for the quantitative data means that the extent to which these findings are transferable, or representative, to other regions within the UK and internationally are limited. The UK, in itself, is geographically diverse, and as such, more data from other 'rural' and 'urban' regions across the country would be needed for increased representation. However, much of the existing literature is limited with samples from one specific area or region, normally in North America or Australia so this marks a welcome addition to the literature. Rather than saying anything definitive, it is hoped that this study will instigate some debate and make way for further research with UK populations.

8.3.5 Scoping Review

Whilst the methods and results from the scoping review identified a gap in the extant literature, notably, that no included studies offered direct insight into self-managing cancer within a rural-urban context in the UK. The databases that were chosen ensured that a wide range of literature in relation to nursing, health and social care, mental health and the behavioural sciences were searched. However, the review was not without its limitations and the search strategy could have been extended to include additional subject specific databases such as the Rural and Remote Health Database via Informit Online, although the host institution did not have access at the time of the research. Furthermore, future searches could consider searching other databases in the health and social sciences such as Academic Search Complete, Allied and Complementary Medicine Database (AMED), Applied Social Sciences Index and Abstracts (ASSIA) and Science Direct. The grey literature was not searched as one of the primary objectives was to map the peer-reviewed academic research in this area. Although to gain a deeper understanding of the field, future reviews should consider exploring the subject-specific grey literature. Given this was not a full systematic review, the review protocol was not registered, however, this could have allowed for initial peer review of proposed methods and increased transparency and awareness of the research. Finally, the search terms could have

been extended to include related terms such as ‘self care’, ‘self help’, ‘self education’ and ‘patient education’, thus ensuring a more comprehensive and thorough search of the academic literature.

8.3.6 Analysis of Questionnaire Free Text Data

The free text data that were collected at the end of the questionnaire offered additional insight into the self-management experiences of participants and can be considered a welcome addition to the data that was collected for this thesis. At the same time, the researcher did not analyse this data in relation to rural-urban residency and so at this time, no definitive conclusions can be made with regard to residency that utilise this data. As is common in quantitative questionnaires, these data were collected to complement existing data and as such, not analysed in this way as it did not explicitly align with the research question(s) and objectives that were posited in the study protocol and at the beginning of this thesis. That is not to say that future analysis should not make use of this data to further enhance understanding of rural-urban differences in people living with and affected by cancer and the researcher plans to do this following the completion of this thesis.

8.4 Recommendations from the Findings

8.4.1 Recommendations for People Living with and Affected by Cancer

- **Physical Activity and Fatigue**: The quantitative data highlighted that participants in both rural and urban areas engaged the least with physical activity behaviours and were least confident when it came to managing fatigue. Individuals need to recognise that fatigue could potentially be a salient concern following cancer treatment and give active consideration to self-management strategies that they might find beneficial. Whilst this is well known and certainly not unique to geography, fatigue and physical activity should be prioritised when identifying the focus of future interventions.
- **Utilising Environment**: The rural or urban environment can act as both a barrier and a facilitator to self-management, depending on the individual. Regardless of residence, people living with and affected by cancer can self-assess their environment so it can be utilised to support their recovery. This can be done through identifying and setting self-management goals (short term and long term) that they wish to achieve. In addition to

this, individuals can consider the sources of support available to them to facilitate these. In areas where services are limited, they should be prepared to think creatively around self-management strategies and potential sources of support.

- **Peer support**: It is important that individuals who want to use their cancer experience to support others are not neglected. The qualitative data highlighted that people benefitted greatly from charity and voluntary work, as well as, attending support groups. Furthermore, some participants were proactive with volunteering and charity work and others reported aspirations to support others. These individuals could potentially be vital to providing support in areas where specialised support is limited.
- **Emotional management**: The data and existing literature suggests that the cancer experience is life changing and for many the emotional side effects often persist much longer than their physical counterparts. It is important to remember that everyone copes in different ways and for those that feel a need to share their experiences, they should give consideration to emotional sources of support that are available from professionals but also within the wider community. It is important that people have some outlet to share problems and concerns in order to avoid deterioration to their mental health.

8.4.2 Recommendations for Health and Social Care Professionals

- **Rediscovering Motivation** - Healthcare providers (and informal support networks) should recognise the importance of motivation and goal setting. They have a considerable role to play when it comes to helping people recovering from cancer to find or rediscover sources of motivation in their life. This can be done through drawing up actions plans in collaboration with the patient about objectives or goals that they wish to achieve. Additionally, it needs to be remembered that people are not always ready to change their behaviour and they need to know when the timing is right, as well as, understanding their reasons (or lack of) for positive behavioural change. Therefore, health professionals, as well as, friends and family, should be supported to have conversations around engaging with health-promoting behaviours with people who are recovering from cancer.
- **Community Involvement** - When discussing recovery from cancer, consideration should be given to some of the positives that can be derived through community involvement and engaging in group activities. Professionals can work collaboratively

to establish an understanding of community support that is available beyond formal service provision. They should be encouraged to look beyond 'cancer' support when signposting people. Whilst promotion of activities over which healthcare providers have no control may make some professionals anxious, there needs to be a good links with credible and well-sustained community activities. With the end goal being a model of integrated care where professionals work collaboratively across primary, secondary, community and tertiary care services.

- **Consideration to Environment** – The challenges of delivering healthcare in rural areas are well documented and the data in this study supports that. However, whilst rural areas may lack physical resources that are found in urban centres, the data in this thesis suggests that they are strong sources of informal and community support. Professionals need to challenge assumptions around rural living where the discourse is predominantly negative. In addition, the conversations that they have with people living with and affected by cancer need to consider the individual's environment, as well as, what community and social factors are already in place. There is room for this to be incorporated into existing holistic needs assessments. For example, the discussions that doctors, nurses and other health professionals have with people living with and affected by cancer about their physical, psychological and social needs could be expanded to explicitly ask about their living environment to ascertain the positives and negatives to this with a view to identifying solutions to support them.
- **The Role of the GP –** GP surgeries function as a hub of activity particularly in rural communities. In this study, participants were more confident to contact their doctor regarding cancer in rural areas, and this was also demonstrated in the interview data. Indeed, if there is limited specialised support in rural areas then it is paramount that health professionals recognise the important role that the GP plays within the local community.

8.4.3 Recommendations for Commissioners

- **Consideration to 'rurality'** – The data has highlighted that there are beneficial services for people affected by cancer in rural areas that are not necessarily formally commissioned. Commissioners needs to give consideration to the positive aspects of

'rural living' and existing formal/informal sources of support. Furthermore, when commissioning services in rural areas an asset-based approach should be adopted, as well as, being informed by a thorough needs assessment. There is a need to think broader than 'cancer support' and link in with what already works and is currently well established within local communities. With rural health being high on the political and policy agenda, healthcare commissioners need to consider the impact of rurality and the positives and negatives when commissioning services for rural populations. These decisions need to be evidence-based and informed by robust research. Equally, the same should be said when considering services within the urban environment and equal weight should be given to both settings to work towards equity of provision and ensure that people who feel isolated in rural or urban environments are not at risk of feeling left behind.

8.4.4 Recommendations for Further Research

- **Collect data on residency** - Future studies with people affected by cancer should consider collecting data on rural-urban residence where appropriate. This can then be utilised to inform interventions and support based on the needs of rural and urban populations. In this study, this was done by asking participants for their post code and cross-referencing with official statistics. This meant that the amount of personal data that was requested was minimal. Indeed, consistency with how this is recorded and analysed would facilitate collaboration amongst researchers and larger datasets for analysis. In particular, more data utilising the same outcomes (HPLP-II; PAM-13; CSSES) in this study, as well as, other validated self-management measures, with diverse and larger samples in the UK and internationally would be welcomed.

- **Perceptions around 'Rural' Research** - There can be negative perceptions around conducting research, as well as, recruiting participants in rural and remote areas. Nonetheless, the split of rural/urban in both the quantitative and qualitative aspect of this study should serve as encouragement to researchers interested in geography and survivorship. This is evidence that those from rural areas are keen to take part in research. Still, researchers will need to be proactive with their recruitment efforts to raise awareness.

- **Concept Analysis of Self-Management –** Future research could benefit from conducting a concept analysis of the term 'self-management' within a cancer context. Whilst existing efforts to define self-management within cancer should be commended these are now a decade old and it could be argued that we still lack a universal and up-to-date definition that has a consistent meaning with both professionals and the public. Given the prevalence of self-management terminology and initiatives it is important that a common language is established as it is likely that this still means different things to different people, and the use of the term 'self' could have negative connotations for some people where they feel like they are on their own.

- **Secondary Data Analysis –** The quantitative and qualitative data that were generated for this thesis offer a range of opportunities for secondary analysis. As mentioned above, the free text data could be analysed comparatively between rural and urban participants to offer further insight into the similarities and differences of having and recovering from cancer in these respective environments. Further multivariate analysis on the quantitative outcomes could be conducted controlling for other factors such as the English Index of Multiple Deprivation (IMD) and Health Deprivation and Disability Score which are easily attainable due to the post codes of participants being collected. Finally, the qualitative interviews generated rich and in-depth data from a diverse sample, on all aspects of the participants' cancer journey which would allow for secondary analysis on a range of other research questions in relation to survivorship, rural-urban residency, self-management and beyond.

8.5 Dissemination and Research Impact

8.5.1 Strategic Dissemination

Firstly, the researcher will continue to work closely with Macmillan Cancer Support to ensure that findings are used to inform policy practice. Links have already been established with the Macmillan Comms at a local and national level, as well as, the Macmillan Evidence Team to ensure that final findings are widely disseminated with people affected by cancer and professionals that support people affected by cancer.

This thesis, along with other Macmillan funded workstreams at the University of Lincoln have been identified and prioritised as a potential high impact case study for submission in the REF2021. Following completion of this thesis, the researcher will collate and document evidence where the findings have been utilised to support people affected by cancer. In addition, there are plans to publish this work in high quality peer reviewed journals. In May 2020, the scoping review (see Chapter 2) was accepted for publication in the journal *Supportive Care in Cancer*. A further manuscript utilising the quantitative findings (see Chapter 5) is in final draft and will be submitted to the *Journal of Rural Health* for consideration in July 2020. This offered some further analysis on cancer-related self-efficacy, health status, as well as, giving consideration to deprivation as a confounding variable. Other potential journals that will be targeted for publication include: *Psycho-Oncology*, *Journal of Cancer Survivorship*, *BMC Cancer*, *European Journal of Cancer Care*.

Initial findings have also been presented at a CNS meeting at University Hospitals of Leicester NHS Trust and the researcher has agreed to return as a guest speaker towards the end of 2020 to report on the final findings from the project. It was important that the findings were fed back into those delivering acute care and all final outputs will be fed back to both recruiting NHS trusts.

Preliminary findings (oral presentation and poster) were presented at the International Psycho Oncology Society Conference (IPOS) in Banff, Canada in September 2019. In addition to this, both abstracts were published in the *Journal of Psychosocial Oncology Research and Practice* (Nelson et al, 2019a; 2019b). The researcher will continue to be proactive about further dissemination opportunities at appropriate conferences such as BPOS 2021, IPOS 2021 and NCRI 2021.

The study was concerned primarily with differences between rural and urban population and so that was the focus of this thesis. That being said, the scope of the data goes far beyond that and there are plans for subsequent analyses with regard to the free-text data from the questionnaire and cross-referencing with quantitative outcomes, as well as, qualitative interview data cross-referenced with the quantitative outcomes.

8.5.2 Additional Dissemination Opportunities

Given the research was in collaboration and part funded by Macmillan Cancer Support, and the researcher was a Macmillan Professional, there were a number of opportunities for dissemination of initial findings available through his professional network.

Firstly, the researcher was an active participant on the Living with and Beyond Cancer Steering Group (based at Lincolnshire West Clinical Commissioning Group) for Lincolnshire throughout the duration of this research. As a result, the researcher and the Director of Studies were invited to speak at the Lincolnshire Cancer Special Interest Group in December 2018 which subsequently led to an invitation to present preliminary findings to the East Midlands Cancer Alliance in 2019. Plans are in place to return and present final data towards the end of 2020.

Furthermore, the researcher was a member of the Steering Group for the Lincolnshire Cancer Summit 2019 which was hosted at the University of Lincoln in June 2019. The event attracted approximately 120 attendees from acute care, allied health, academia and beyond. Preliminary findings from this research were presented as a keynote speech, as well as, in one of the workshops. Unfortunately, due to the COVID-19 pandemic, the 2020 Cancer Summit was cancelled. However, plans are already in place to support and host the event at the University of Lincoln in 2021. The researcher will continue to sit on the Steering Group as the representative for the University to support another successful event where further findings from this thesis will be disseminated.

The initial outcomes from this research led to the researcher being successful in seeking and obtaining £19, 120 from Macmillan Cancer Support to conduct a new project on the Learning and Development (L&D) needs of people affected by cancer. This study was completed in May 2020 and preliminary findings have also been presented informally to Macmillan HOPE Facilitators and Macmillan Volunteers. The researcher was also invited to present at a number of Macmillan events for professionals towards the end of 2019 in Derby and Chesterfield.

8.6 Personal Reflection

According to Hanrahan et al, (1999) the purpose of doctoral research can be twofold. Firstly, and somewhat the most prominent, the student researcher is to undertake and produce an original and substantive piece of research that contributes to knowledge within the given field. Secondly, whilst perhaps less explicit, is for the student researcher to become proficient in the process of conducting research independently in an ethical manner. For the purposes of this section of the thesis, the writing style will now switch to the first person in order to reflect on the personal experiences of the student researcher. Whilst this is by no means considered to be an exhaustive reflective account, these are what the researcher considered to be the most salient areas of their own personal development.

When I began this PhD journey in 2016, I was equally excited and intimidated at the prospect of undertaking doctoral research in the health sciences. Whilst I already had two years' experience as a Research Assistant at the University of Strathclyde and the University of Lincoln, I very much considered myself a novice researcher who had much to learn about the field of cancer survivorship, self-management, research design and methodology. On reflection, I am still very much excited by research, if not more so than when I began this thesis, and somewhat less intimidated, which I take as a very good sign for my prospective future research career.

Having come from a different discipline that relied heavily on post-positivist quantitative research methods, I had never had the opportunity to take qualitative methods out of the classroom and apply them until I joined the University of Lincoln in March 2014. It was here that I got my first experience in the formal application of qualitative methods and analysing qualitative data on a number of local research projects. Having since had over five years' experience with qualitative research, much of which, was during the writing of this thesis, I now pride myself on my ability to conduct research interviews with a wide range of different people. It has taken patience and practice, but I understand that 'good' interviewing is a skill and I think that I am improving all of the time. I feel I am good at sitting in a room with a complete stranger and having a meaningful discussion without overstepping the line or coming across as invasive. At the same time, talking to people about cancer is not always easy, for the participant and the interviewer. However, I try to always remind myself that so much positivity comes out of the data and people's willingness to give up their time with no reward, never ceases to amaze me. I feel very privileged to have met the participants who have helped me with data collection for this study, as if it were not for this research, it is unlikely that our paths would have crossed. Indeed, people have shared some very personal stories with me, some of which they don't even tell their close friends and family and for me, that is a very special position to be in. I do hope that the findings from this research, as well as, any subsequent projects that it informs, will go on to help improve the lives of people affected by cancer.

I often find analysing qualitative data to be overwhelming and exhausting, however, I no longer subscribe to the view that we should have a world where quantitative and qualitative approaches to research should exist in isolation. The findings from this thesis have perhaps demonstrated that to me more than any textbook ever has. Equally, in the past, I wrongly perceived quantitative methods as somewhat 'right' or wrong' and I no longer hold that position. When writing up my quantitative results, I took advice from a number of colleagues who were experienced in statistics from a range of disciplines, yet I received a different answer from everyone about how I should conduct my analysis. Much like all research, quantitative methods are not immune to interpretation and debate. Nonetheless, something that I did learn from the people I spoke to was the importance of presenting the approach to analysis, as well as, the analysis itself and the results in a transparent and comprehensive manner. It is my hope that I have done just that.

I quickly learnt as I talked to my colleagues and fellow doctoral students that no research is easy. In my case, I have been very lucky to have had the support of a Project Steering Group that included a patient representative, as well as, PPI involvement. Whilst managing the steering group at times was challenging, given the number of different people and opinions in the room, I hope that this finished research has done justice to the important discussions and valuable input that all members brought. Not all doctoral students have this privilege and it has been so important in helping with all aspects of the design. Challenging though it was, as a lot was thrown at me during these discussions, I know that the research is better as a result of being guided by a steering group as are the on-going plans for dissemination and impact generation.

In has been an honour to work with, and for, Macmillan Cancer Support over the last four years and I continue to see first-hand all the great work they do on a daily basis to improve the lives of people living with and affected by cancer. I am delighted to be continuing my role as a Macmillan Professional working on a new project looking at learning and development in people affected by cancer. This was a positive outcome that has come from this doctoral research where I was successful in applying for additional funds to take this new research forward as the Principal Investigator. Furthermore, I am also in talks with the Lincolnshire West CCG to develop a patient experience resource utilising data from this thesis and I hope that this exciting and beneficial work will come to fruition in 2020.

On a personal level, this process has also resulted in me getting involved with event management. I was part of the Steering Group for the Lincolnshire Cancer Summit 2019. It was a pleasure to be part of this hugely successful event that was hosted at the University of Lincoln. This also gave me an opportunity to present my findings, and to get involved with facilitating workshops. Plans are already in place for next year's event, which will be held again at the University of Lincoln and I will continue to sit on the Steering Group. Furthermore, I hope to present final findings from this thesis there in June 2020.

I have learnt that skills such as patience and persistence are just as vital as training in 'research methods' when it comes to conducting research in healthcare. To get this project completed I had to utilise a lot of existing contacts effectively, as well as, establishing and building a number of new relationships. I never would have dreamed that I could go out and speak to health professionals about

research findings but now that has almost become a routine element of my role as a researcher and one that I am no longer as daunted by.

This research has also taught me to be dismissive of saturation in qualitative research. The idea that we stop when we continue to hear the same thing from participants is to me, at odds with good research. Whilst I was about halfway through my interviews, I thought, I had reached saturation, however, I then began to uncover some new findings, until again very near the end, I thought I had reached saturation, but again, the last two to three interviews I conducted gave way to some very interesting data that I otherwise would not have captured.

Near the end of this PhD journey I was delighted to be given the opportunity to present preliminary findings from this thesis at the International Psycho-Oncology Society (IPOS) in Banff, Canada. To have two abstracts accepted at this prestigious conference and published in the Journal of Psychosocial Oncology Research and Practice was a real honour. More so, it was a privilege to present in the same session as Professor Claire Foster who leads the Macmillan Survivorship Research Group at University of Southampton whom much of their work has informed this thesis. Initial findings from this research have also found their way to the Rethinking Remote Conference in Inverness (May 2018) and the NCRI Conference in Glasgow (November 2018), as well as, a number of local and national, Macmillan Cancer Support events. It is my hope that next year these findings reach further audiences through conference dissemination and are published in high impact peer reviewed academic journals.

Additionally, towards the end of this process, a personal outcome was that I was nominated by colleagues to receive a University of Lincoln, Vice Chancellor's Award for 'Public Engagement with Research.' I will receive this in November 2019 and I was really delighted to be recognised for my engagement efforts with stakeholders and people affected by cancer, however, it would not have been possible without all of the wonderful research participants, volunteers, academic colleagues and research professionals that I continue to work with on a daily basis, thank you.

I have been extremely fortunate to continue to enhance my academic profile and teaching experience during these last years through teaching on a range of undergraduate and postgraduate programmes across the School of Health and Social Care. This has given me the opportunity to transfer my experiences as a researcher, notably, those from this doctoral thesis. I have also been delighted to supervise a number of undergraduate student dissertations in the field of cancer survivorship and I hope that I have gone some way to inspiring some future academics and health professionals to undertake careers that will benefit people affected by cancer.

I hope I have done justice to all the people who took the time to complete a questionnaire and take part in an interview. It is a real privilege to be invited into your homes and for you to share such personal experiences with me, a complete stranger. It is my hope, that the findings from this thesis and subsequent publications can be used to benefit people affected by cancer, so again, thank you!

To finish, I would like to reflect on my own views around the terminology of 'self-management'. When I began this study, I felt I was a true advocate of 'self-management' and wanted to play my part in supporting people affected by cancer to 'self-manage' their health and health care. On reflection, I still

endorse what self-management stands for conceptually, that is, supporting people to be actively engaged in managing a long-term condition and practising behaviours that promote health and wellbeing. However, I feel the terminology can be misleading, the key being in the 'self' manage. In some of my discussions with people affected by cancer, they associate 'self-management' with being 'on their own' or 'getting on with it' which is somewhat at odds with the collaborative approach identified in the academic literature where self-management rests heavily with the individual who is supported by professionals. Much of the qualitative data in this thesis was concerned with 'peer support', 'communication', 'community' none of which are individualistic in essence. I often think calling an event something that 'supports self-management' or is about 'learning self-management' could imply that you are going to be taught how to 'get on with it' 'on your own' so I think there needs to be further discussions around the branding of support going forward.

8.7 Conclusion to Chapter

This final chapter has provided an overview of this thesis, as well as, a number of pertinent limitations to this study that should be considered. Furthermore, a series of recommendations that were drawn from the findings were reported on.

The majority of the barriers and facilitators that were identified were not necessarily unique to the urban or rural environment. Certainly, the qualitative data show that residency is not as unequivocal as the quantitative results would suggest. The mixed methods design has therefore led to different conclusions that would not have been possible had either quantitative or qualitative methods been used in isolation. This study was specific to the East Midlands area in England so the extent to which findings are transferable to the rest of the UK or internationally are debatable. However, hopefully the findings from this thesis and subsequent research will open the door for researchers to conduct further work in this area.

Engagement with the local community was greater in rural areas which could account for the differences. Whilst the active treatment phase can present considerable challenges for people affected by cancer in rural areas the findings suggest that the rural environment has the potential to increase engagement with health-behaviours and self-management in the transition to survivorship.

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UNIVERSITY OF
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A RURAL-URBAN COMPARISON OF SELF-MANAGEMENT IN PEOPLE AFFECTED BY CANCER FOLLOWING TREATMENT: A MIXED METHODS STUDY

APPENDICES

David Nelson

July 2020

APPENDIX 1: EXAMPLE OF PGR PROGRESS REPORT

UNIVERSITY OF LINCOLN

PGR Progress Meeting Report
Monthly for Full-time, every 2 months for Part-Time

Please give the student, supervisors and school office a copy of this completed form.

Student Name	David Nelson
Student ID	1 4 5 7 8 9 8 9
College	College of Social Science
School	School of Health and Social Care
Enrolment Date	03/01/2016
Student Status	Home
Mode of Study	Full time

To be completed by supervisor and student

Programme	PhD Direct
Date of meeting	26/09/2017
Meeting format	☒ Face to Face ☐ Telephone ☐ Email ☐ Skype ☐ Other Click here to enter text.
End of period of registration	06/01/2020

Summary of current situation (including identification of particular strengths and weaknesses and completion of actions from previous meeting	Current quantitative sample n=215. Whilst a handful of questionnaires are still being returned it is unlikely that the response rate for the quantitative work will increase significantly. All questionnaires to date have been coded. To explore alternative options to increase sample size. DN presented research poster and three minute elevator pitch at Macmillan Leading the Way in Self-Management Conference in Birmingham 17th October 2017. DN and IMG have been working on systematic review paper with LIH. DN has extracted all data into EndNote, duplicates excluded and all titles have been screened. DN and IMG now screening abstracts against inclusion criteria. DN sent draft of protocol to LIH for review and following amendments this has now been registered on Prospero and is currently being assessed. DN has started contacting participants for qualitative interviews. Prior to this DN checked with data team at ULHT to ensure that we did not cause undue distress by contacting participants who no longer met the inclusion/exclusion criteria. The same will be done for participants at UHL.
Summary of advice	DN, CJ and IMG all attended supervision at Sarah Swift Building on 24/10/17 DN provided research update and overview of initial results – descriptive statistics and t tests from the quantitative data. As discussed at previous meeting, given delays in data collection at ULHT and UHL – qual work should commence prior to phase one completion. Interviews are now being arranged and qual data collection has commenced. DN to redraft methods chapter and send to team.

Future training needs analysis and ethical approval issues	DN has completed systematic review training hosted by LIH and will continue to work with their team to produce a qual systematic review.
	All ethical approvals currently in place
	Should an alternative recruitment strategy be put in place to increase the quantitative sample, a substantial amendment would have to be submitted to HRA/NHS REC.

Actions to be taken

By student	Continue to monitor response rate and contine coding questionnaires over the coming weeks.
	Explore possible alternative recruitment strategies to increase response rate – contact UHL and ULHT regarding this. One potential option is an online survey using Qualtrics software.
	DN to meet with Ruth Willis, Macmillan Partnership Manager to provide research update and discuss plans over the coming months.
	Contact potential participants across Lincolnshire and surrounding areas for qualitative work. Conduct interviews and transcribe. Target of at least ten interviews prior to Christmas.
	Continue working on methods and submit to RK, IMG, CJ for comment.
	Meet weekly with IMG and monthly with Lincoln Institue of Health support team to work on qualitative review paper that will contribute to PhD.
	Explore potential ideas for a paper with RK, IMG, CJ and Clinical fellows re open text response on questionnaire.
	Abstract submission to BPOS for November 10th.

Attend NCRI Conference in Liverpool 6th-8th November.

By supervisor	RK, IMG and CJ to read and provide feedback on material prior to next supervision. IMG to meet with DN weekly to progress review paper. All to have a think re open text response paper on questionnaire and how best to proceed. Maintain frequent contact via email should any other issues arise.
Proposed date of next meeting	29/11/2017

I certify this is a true record of the meeting. I also understand the University will retain a copy of this report on my student file for future reference if required.

Student signature  Date 01/11/2017

Supervisor signature  Date 01/11/2017

Name Ros Kane

APPENDIX 2: EXAMPLE OF PROJECT STEERING GROUP MINUTES

Macmillan Cancer Support and University of Lincoln

Self-Management Research Steering Group

University of Lincoln, Sarah Swift Building (SSB4101)

Minutes from Monday 24th July 2017

12-2pm

In attendance:

Dr Ros Kane (UofL)

Dr Christine Jackson (Minutes, UofL)

Dr Ian McGonagle (UofL)

David Nelson (Chair, UofL)

Kathie Longbone (Lincolnshire West CCG)

Caroline Boyer (Macmillan Cancer Support)

Ruth Willis (Macmillan Cancer Support)

1. Apologies

DN welcomed all and noted apologies from Sarah Ward (ULHT); Jan Pascal (Keele); Denise Doyle; Sarah Morley; Cathy Henshall (Oxford Brookes) Sarah Morley (UHL); Jane Pickard (UHL).

Note: Ruth Willis is replacing Kathy Blythe.

2. Minutes from previous meeting

DN went through the minutes and any actions from the previous meeting held on 13th March 2017, University of Lincoln. DN presented an overview of ethical process. Branding was to be agreed at later meetings.

All actions complete.

3. Research update

DN reported that recruitment at ULHT was going well and thanks to Sarah Ward and the Cancer Centre Staff there for all of their help. SW confirmed mailout on 13th July 2017.

With regards to Leicester there have been some delays from their R&D office requesting changes to the documentation and the status of UHL as a "recruiting site" as opposed to "PIC" site. This will need to be resubmitted to R&D by DN. RK suggested making a phone call to HRA re this.

Action: DN to continue to liaise with HRA, UHL R&D and make necessary changes to begin recruitment at that site.

DN spoke to Sarah Ward prior to the meeting. DN reported that 417 questionnaires were posted to a random sample of ULT patients. Initial response has been very positive with 84 completed questionnaires returned. To date, 50 have been coded. 52% have opted in for the qualitative work. 52% female; 48% male. Mean age is 70 years. Very little missing data which is also encouraging.

DN hoping to begin qualitative work in November 2017. Around 30 participants. Given option of telephone or F2F interview. Also, Skype.

4. Follow up with ULHT; Access to data

DN to keep a record of ID codes for qual work and recheck against inclusion criteria with both cancer centres. Additionally, to send summary of results.

Action: DN to contact both Cancer Centres to check participant status against inclusion/exclusion criteria prior to commencing qualitative recruitment.

DN need's to arrange payment to the trust for postage and staff time. Invoice for payment (0.67 x £417 = £280). The same or similar for Leicester. Send invoice to DN to process through finance office quoting the NSG no.

Action: DN to follow up with Sarah about costings for time and involvement.

5. Dissemination

DN reported that 2 conference abstracts have been rejected – likely down to a lack of data being reported. DN will resubmit abstracts to NCRI 2018 with completed data.

DN submitted Macmillan Learnzone grant application.

DN to present at British Sociological Sports Study Group Conference, UofL.

The group discussed a summary sheet that could be sent to participants. There was a discussion around wider dissemination and branding – CNS's, academic audience, H&SC professionals, patients. RK suggested this will all feed into developing an impact case study.

Action: DN to contact local and national comms teams to put a plan in place.

6. Research impact

RK identified the Macmillan research as a potential impact case study to be developed and drafted up.

KL felt the research will influence future Macmillan work streams, to provide evidence of indicators towards best practice for self-management.

IMG suggested that we need to consider how the findings can be fed into service redesign and changes to service delivery. CB suggested linking in with SW regarding impact

Action: Impact to remain on the agenda for future meetings

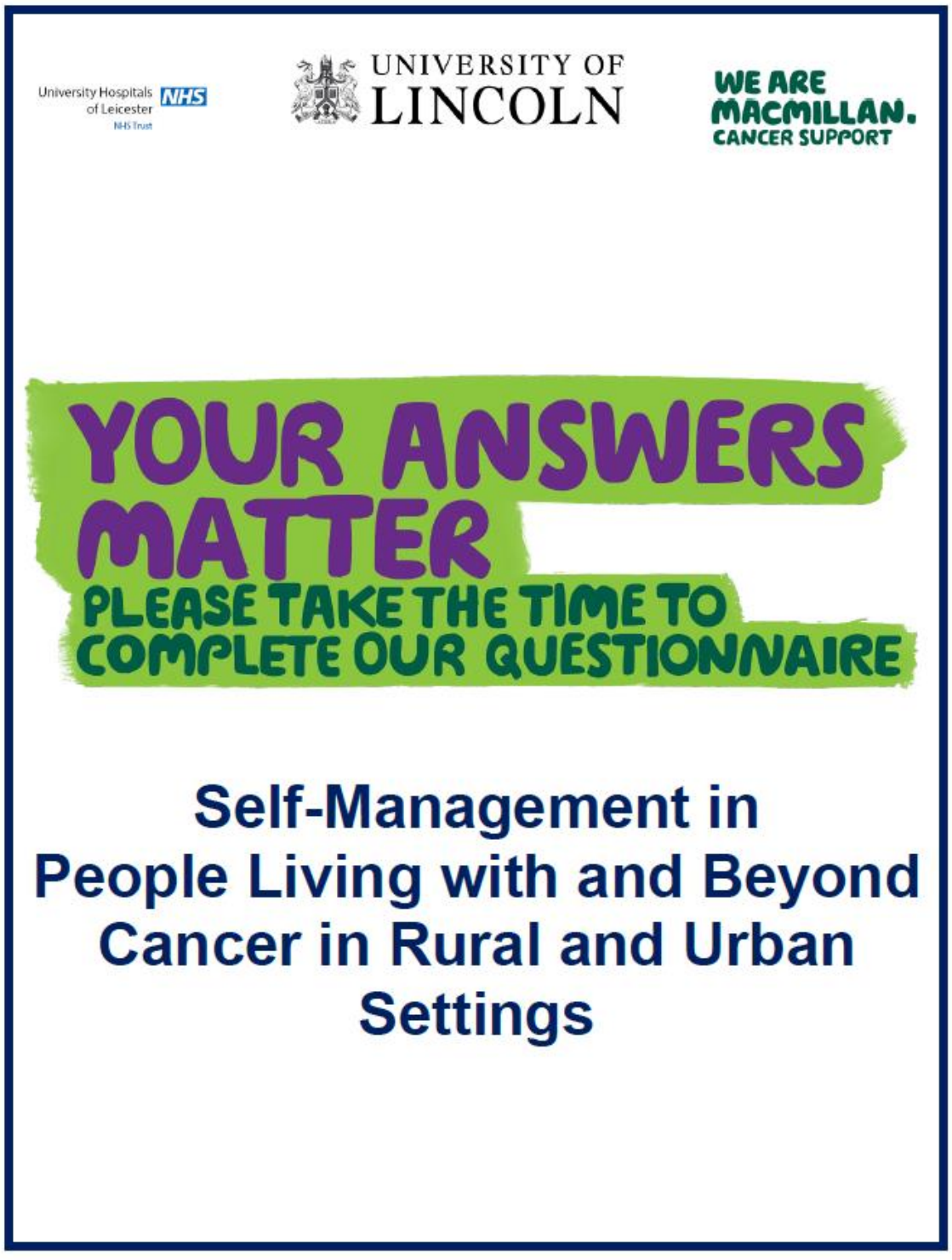
7. Date of next meeting and any actions from meeting

Monday 30th October 2017, 12-2pm

AOB:

Remove Kathy Blythe from Steering group circulation and add Ruth Willis.

APPENDIX 3: SELF-COMPLETION POSTAL QUESTIONNAIRE



Questionnaire (Version 2.0; 16/02/2017): Self-Management in People Living with and Beyond Cancer in Rural and Urban Settings

Thank you for agreeing to take part in this study about how people living with and beyond cancer manage their health following cancer treatment.

We know we are asking you to provide a lot of information about yourself and your experiences, but the information you provide is very important for us to identify and understand the differences in how people affected by cancer manage their health and health care after treatment.

Who should complete this questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Some questions require you to circle your response. Again if you make a mistake; cross out the mistake and circle the correct answer. We ask that you do your best to try and answer all the questions.

We wish to access your medical records to gain more information about your diagnosis and treatment for cancer. All information accessed will be treated confidentiality and anonymised. **By completing and returning this questionnaire, you are giving your consent for the research team to have access to your relevant health information for the purposes of this study.**

We would also like to use the information you have provided for this study in future research in the field of cancer survivorship and self-management. Please be assured that should any information be used in other studies or shared with external partners that it will be presented in anonymous form. **By completing and returning this questionnaire, you are giving your consent for the information provided to be used in future research studies and shared anonymously with internal and external partners where appropriate.**

If you would prefer, you may also complete this survey over the telephone or return via email to the research team. To do this, please contact David Nelson on 01522 837343 or scan and send your response to dnelson@lincoln.ac.uk

Taking part in this questionnaire is voluntary

Published reports will not contain any personal details

ID NUMBER: *(To be completed by NHS Trust Staff)*

QUESTIONNAIRE BEGINS ON NEXT PAGE

START OF QUESTIONNAIRE

SECTION 1: ABOUT YOU

1. What is your date of birth? (Please write in)
   (DD/MM/YY)

2. What is your gender?

- ☐ Female
- ☐ Male
- ☐ Other gender identity
- ☐ Prefer not to say

3. What is your ethnic group?
   Choose one option that best describes your ethnic group or background

White
- ☐ English, Welsh, Scottish, Northern Irish, British
- ☐ Irish
- ☐ Traveller
- ☐ Any other White background (please describe).....

Mixed/Multiple ethnic groups
- ☐ White and Black Carribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/Multiple ethnic background (please describe).....

Asian/Asian British
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background (please describe).....

Black/African/Caribbean/Black British
- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/Caribbean background (please describe).....

Other ethnic group
- ☐ Arab
- ☐ Any other ethnic group (please describe).....

4. What is your religion?

- ☐ No Religion

- [ ] Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- [ ] Buddhist
- [ ] Hindu
- [ ] Jewish
- [ ] Muslim
- [ ] Sikh
- [ ] Any other religion (please describe).....

5. Which statement best describes your living arrangements?

- [ ] I live with partner/spouse/family/friends
- [ ] I live alone
- [ ] I live in a nursing home, hospital, or other long term care home
- [ ] Other (please describe).....

6. What is your current marital status?

- [ ] Married/Civil Partnership
- [ ] Living with partner
- [ ] Widowed
- [ ] Single
- [ ] Divorced/Separated

7. What is your current employment status?

- [ ] Employed
- [ ] Not Employed
- [ ] Retired
- [ ] Other (please specify).....

8. Which of these qualifications do you have? (please tick all that apply)

- [ ] 1-4 O levels/CSEs/GCSEs (any grades), Entry Level, Foundation Diploma
- [ ] NVQ Level 1, Foundation GNVQ, Basic Skills
- [ ] 5+ O levels (passes)/CSEs (grade 1)/GCSEs (grades A*-C), School Certificate, 1 A level/ 2-3 AS levels/ VCEs, Higher Diploma
- [ ] NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/ General Diploma, RSA Diploma
- [ ] Apprenticeship
- [ ] 2+ A levels/VCEs, 4+AS levels, Higher School Certificate, Progression/ Advanced Diploma

- [ ] NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma
- [ ] Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE)
- [ ] NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level
- [ ] Professional qualifications (for example teaching, nursing, accountancy)
- [ ] Other vocational/ work-related qualifications
- [ ] Foreign qualifications
- [ ] No qualifications
- [ ] Other qualifications (please specify).....

9. What is your annual household income?

- [ ] £0-£14,999
- [ ] £15-24,999
- [ ] £25-49,999
- [ ] £50-74,999
- [ ] Over £75,000

10. What is your post code? (Please write in)

11. How is your health in general?

- [ ] Very Good
- [ ] Good
- [ ] Fair
- [ ] Poor
- [ ] Very Poor

QUESTIONNAIRE CONTINUES ON NEXT PAGE

SECTION 2: HEALTH PROMOTING BEHAVIOURS

DIRECTIONS: This questionnaire contains statements about your *present* way of life or personal habits. Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behavior by circling:

N for never, **S** for sometimes, **O** for often, or **R** for routinely

		NEVER	SOMETIMES	OFTEN	ROUTINELY
1.	Discuss my problems and concerns with people close to me.	N	S	O	R
2.	Choose a diet low in fat, saturated fat, and cholesterol.	N	S	O	R
3.	Report any unusual signs or symptoms to a physician or other health professional.	N	S	O	R
4.	Follow a planned exercise program.	N	S	O	R
5.	Get enough sleep.	N	S	O	R
6.	Feel I am growing and changing in positive ways.	N	S	O	R
7.	Praise other people easily for their achievements.	N	S	O	R
8.	Limit use of sugars and food containing sugar (sweets).	N	S	O	R
9.	Read or watch TV programs about improving health.	N	S	O	R
10.	Exercise vigorously for 20 or more minutes at least three times a week (such as brisk walking, bicycling, aerobic dancing, using a stair climber).	N	S	O	R
11.	Take some time for relaxation each day.	N	S	O	R
12.	Believe that my life has purpose.	N	S	O	R
13.	Maintain meaningful and fulfilling relationships with others.	N	S	O	R
14.	Eat 6-11 servings of bread, cereal, rice and pasta each day.	N	S	O	R
15.	Question health professionals in order to understand their instructions.	N	S	O	R
16.	Take part in light to moderate physical activity (such as sustained walking 30-40 minutes 5 or more times a week).	N	S	O	R
17.	Accept those things in my life which I can not change.	N	S	O	R
18.	Look forward to the future.	N	S	O	R
19.	Spend time with close friends.	N	S	O	R
20.	Eat 2-4 servings of fruit each day.	N	S	O	R
21.	Get a second opinion when I question my health care provider's advice.	N	S	O	R
22.	Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling).	N	S	O	R
23.	Concentrate on pleasant thoughts at bedtime.	N	S	O	R
24.	Feel content and at peace with myself.	N	S	O	R
25.	Find it easy to show concern, love and warmth to others.	N	S	O	R

	NEVER	SOMETIMES	OFTEN	ROUTINELY
26. Eat 3-5 servings of vegetables each day.	N	S	O	R
27. Discuss my health concerns with health professionals.	N	S	O	R
28. Do stretching exercises at least 3 times per week.	N	S	O	R
29. Use specific methods to control my stress.	N	S	O	R
30. Work toward long-term goals in my life.	N	S	O	R
31. Touch and am touched by people I care about.	N	S	O	R
32. Eat 2-3 servings of milk, yogurt or cheese each day.	N	S	O	R
33. Inspect my body at least monthly for physical changes/danger signs.	N	S	O	R
34. Get exercise during usual daily activities (such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking).	N	S	O	R
35. Balance time between work and play.	N	S	O	R
36. Find each day interesting and challenging.	N	S	O	R
37. Find ways to meet my needs for intimacy.	N	S	O	R
38. Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and nuts group each day.	N	S	O	R
39. Ask for information from health professionals about how to take good care of myself.	N	S	O	R
40. Check my pulse rate when exercising.	N	S	O	R
41. Practice relaxation or meditation for 15-20 minutes daily.	N	S	O	R
42. Am aware of what is important to me in life.	N	S	O	R
43. Get support from a network of caring people.	N	S	O	R
44. Read labels to identify nutrients, fats, and sodium content in packaged food.	N	S	O	R
45. Attend educational programs on personal health care.	N	S	O	R
46. Reach my target heart rate when exercising.	N	S	O	R
47. Pace myself to prevent tiredness.	N	S	O	R
48. Feel connected with some force greater than myself.	N	S	O	R
49. Settle conflicts with others through discussion and compromise.	N	S	O	R
50. Eat breakfast.	N	S	O	R
51. Seek guidance or counseling when necessary.	N	S	O	R
52. Expose myself to new experiences and challenges.	N	S	O	R

SECTION 3: MANAGING YOUR HEALTH AND HEALTH CARE

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, circle N/A.

1.	I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can carry out medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I understand my health problems and what causes them	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I have been able to maintain lifestyle changes, like healthy eating or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11.	I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12.	I am confident I can work out solutions when new problems arise with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

SECTION 4: CONFIDENCE TO MANAGE YOUR HEALTH

We would like to know how confident you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1 . How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

2 . How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

3 . How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

4 . How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

5 . How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

6 . How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

7. How confident are you that you can access information about your cancer and any effects of the diagnosis and treatment?

8. How confident are you that you can access people to help and support you when you have problems caused by cancer and/or cancer treatment?

9. How confident are you that you can deal with the problems cancer and/or cancer treatment has caused by yourself?

10. How confident are you to contact your doctor about problems caused by your cancer/treatment?

11. How confident are you that you can get support with problems caused by your cancer/treatment from health and/or social care professionals?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

Questions 1-6 developed by the Stanford Patent Education Research Centre.
***Questions 7-11 developed by the Macmillan Survivorship Research Group, University of Southampton.*

SECTION 5: FURTHER INFORMATION

Thinking about how you manage your health and health care, if there is anything else you would like to tell us about your experience, please write in the box below.

☐ Finally, if you would like us to send you a summary of the study findings at the end of the research please tick this box.

PLEASE FOLD THE QUESTIONNAIRE AND RETURN IN THE ENVELOPE PROVIDED

THANK YOU FOR TAKING THE TIME TO ANSWER THESE QUESTIONS

END OF QUESTIONNAIRE

APPENDIX 4: INTERVIEW TOPIC GUIDE

Introduce the study; go through PIS; consent; confidentiality; timing. Outline structure of interview.

Give the participant time to ask any questions. Re-iterate that participant can refuse to answer any questions and is free to terminate the interview at any time.

SECTION 1: BACKGROUND

Q1. Background/Introduction

Q2. When were you first diagnosed with cancer?

Q3. What treatment have you received for cancer and where?

Q4. When did treatment end?

Q5. What sort of follow up care have you been involved with?

Q6. Other long-term health conditions?

SECTION 2: SELF-MANAGEMENT

Q7. What does the term self-management mean to you?

Q8. What sort of tasks do you engage with to manage your health? (Emotional; Roles and Relationships; Medical)

- Before you were diagnosed
- During treatment
- After treatment

Q9. Health Behaviours: Physical Activity; Diet/Nutrition; Stress/Relaxation Management; Spiritual; Interpersonal relationships; Health Responsibility; Support Groups/Educational events

Q10. Who/What help or enables you to manage your health? GP; H&SC Professionals been involved with? Motivation? Facilitators? Are you confident in managing your health?

Q11. Do you feel you have been well informed, have the appropriate knowledge about how you can manage the consequences of cancer or your health more broadly in general?

Q12. Is there anything that prevents you from managing your health and health care? Any barriers?

Q13. Do you have any health needs that are currently not being met?

SECTION 3: RURAL/URBAN

Q14. How would you define where you live?

Q15. Does where you live have an impact on your ability to manage your health? Does it help or prevent aspects of how you manage your health and health care?

Q16. Accessibility/Ease of access for support?

Q17. Do you engage with any local support services for cancer or more broadly with regards to your health?

Q18. Is there anything you would like to see in place at a local or even a national level?

SECTION 4: CLOSE

Finally, is there anything we've left out that you would like to add?

Many thanks for your time. Interview ends.

APPENDIX 5: PATIENT AND PUBLIC INVOLVEMENT (PPI) HANDOUT

ARE YOU INTERESTED IN SELF-MANAGEMENT AND CANCER RESEARCH?

WOULD YOU LIKE TO JOIN A PATIENT AND PUBLIC INVOLVEMENT (PPI) GROUP?

UNIVERSITY OF LINCOLN

Who we are?

We are a group of researchers from the University of Lincoln with funding from Macmillan Cancer Support and we are interested in the motivations of people living with and beyond cancer to self-manage following treatment.

Self-management can mean different things to different people and we would like to understand what it means to people affected by cancer.

The best way to find out this information is to form a patient and public involvement (PPI) group.

We would like to hear from?

People who have had a diagnosis or who have experience of a partner or close family member diagnosed with cancer.

Why join a PPI group?

Researchers are becoming increasingly aware of the importance and value of involving patients and healthcare service users in their work.

By joining the group you can use your experiences to help us design the study and ensure it is as relevant as possible to people affected by cancer.

You can work with us to plan and design the research – **it is not about taking part in actual research.**

WE ARE MACMILLAN. CANCER SUPPORT

To find out what this would involve or to register your interest please contact:

David Nelson
Macmillan Research Fellow
Tel: 01522 83 7343
Email: dnelson@lincoln.ac.uk

APPENDIX 6: EMAIL COMMENTS FROM PPI VOLUNTEER

From: XXXXXXXXXX
To: David Nelson
Subject: Feedback
Date: 18 December 2016 19:28:05

Good evening David,

Well your information made for an interesting read and I think this is going to be really useful research as I hear striking differences in experiences, routines and attitudes between various individuals and groups I meet up with and I know my own outlooks and behaviours have changed and continue to be influenced and changed. For me this has been a slow process which is due to my own outlooks as well as not knowing about what to do and where to turn. My attitudes are also very much effected by outside influences such as a busy family life, work and the side effects of medication. This will always be a very individual thing.

Firstly, I read everything through and the only editorial issue I can see is section 2 question 34 where I think 'parting' should read as 'parking' and the email address for [Name Revoved] in the participation information sheet doesn't show in blue like the others.

I personally do not agree with the reminder letter as I think 2 weeks is sufficient time to respond and if someone is keen they have got enough time to complete the research. I also think that depending on what someone is experiencing and where they are in their treatment may mean that a reminder letter could cause upset as not everyone is going to be able to think straight about involvement in research until they can mentally cope with it. If you think you'll only get a 20-30% return could you send out to more people rather than chase up those who do not respond in time?

Secondly, I then completed the research as though I had received it and even being already familiar with the questions and layout as well as working through the forms quickly it took me 16 minutes so I don't think the expected 15-20 minutes suggested is realistic and I would personally prefer a fairer indication of how long the research would take me when deciding to take part or not.

I hope this is helpful and I haven't gone on too much, (name removed)

Sent from my iPad

APPENDIX 7: STUDY PROTOCOL

Health Research Authority

FULL TITLE: Self-management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study

SHORT TITLE: SELF-MANAGEMENT IN PEOPLE LWABC IN RURAL AND URBAN SETTINGS

Protocol Version: 1.0

Date: 21/02/2017

This protocol has regard for the HRA guidance.

FULL TITLE OF THE STUDY

Self-Management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study.

SHORT STUDY TITLE

Self-Management in People LWABC in Rural and Urban Settings.

PROTOCOL VERSION NUMBER AND DATE

Protocol Version: 1.0

Date: 21/02/2017

RESEARCH REFERENCE NUMBERS

IRAS Number: 204679

SPONSORS Number: 280755 (University of Lincoln, AMS Record ID No.)

R&D Reference Number: 181016Nelson (United Lincolnshire Hospitals NHS Trust)

Funder's Reference Number: 5183969 (Macmillan Cancer Support, NSG No.)

CHIEF INVESTIGATOR

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SPONSOR

Mr Nigel Horner, Head of School of Health and Social Care

University of Lincoln, College of Social Science

Brayford Pool, Lincoln

Lincolnshire

LN6 7TS

E: nhorner@lincoln.ac.uk

T: 01522 837443

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Date: 21/02/17

Signature: 

Name (please print):

Ros Kane

Position: Reader in Healthcare

Chief Investigator:

Date: 21/02/17

Signature: 

Name: (please print):

David Nelson

Position: Macmillan Research Fellow/PhD Student

KEY STUDY CONTACTS

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STUDY SUMMARY

Study Title	Self-management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study
Short title	Self-management in People LWABC in Rural and Urban Settings v.1.0.
Study Design	The study is a cross-sectional, mixed methods design incorporating two phases. Phase 1 consists of a quantitative survey collecting data on health promoting behaviours, patient activation and self-efficacy. Phase 2 involves a series of qualitative interviews that aim to identify, and explore, the barriers and facilitators to self-management in rural and urban settings.
Study Participants	Participants will be recruited via the cancer patient database at United Lincolnshire Hospitals NHS Trust and University Hospitals of Leicester NHS Trust. They will have had a confirmed diagnosis of cancer and have undergone primary cancer treatment (encompassing either chemotherapy, radiotherapy or surgery), which must have ended at least 12 months previously but no more than 5 years ago.
Planned Size of Sample	Phase 1: Quantitative sample (n=600) Phase 2: Qualitative sample (n=30)
Follow up duration	In phase 1, participants will be sent a self-completion postal survey. If no response is received within two weeks a reminder letter will be sent. If no response has been received after a further two weeks, then no additional correspondence will be made. Once all surveys have been received and analysed, a sample of survey respondents (who have registered their interest in being interviewed) will be contacted and invited to take part in phase 2, a qualitative discussion. It is expected that participants would be involved in the research for approximately 6 months. Finally, all participants will be given the opportunity to receive a summary of the research findings. After this, there will be no further follow up.
Planned Study Period	02/01/2017 – 31/08/2019
Research Aims	The study will be undertaken to (a) identify and compare health promoting behaviours in cancer survivors from a rural and urban setting (b) identify and compare patient activation in cancer survivors from a rural and urban setting (c) identify and compare self-management self-efficacy in cancer survivors from a rural and urban setting (d) to explore the relationship between self-management practices, patient activation and self-efficacy and (e) to identify, and compare, the barriers and facilitators to self-management in a rural and urban setting.

FUNDING AND SUPPORT IN KIND

FUNDERS	FINANCIAL AND NON FINANCIAL SUPPORT GIVEN
Macmillan Cancer Support Kathy Blythe, Macmillan Partnership Manager Email: kblythe@macmillan.org.uk Tel: 01529307251	**Financial Support** Macmillan Cancer Support have appointed the Chief Investigator (David Nelson) to the post of Macmillan Research Fellow, band 6, WTE 1.0 based at the University of Lincoln from 1 October 2015 to 1 October 2018. Macmillan will financially contribute 1.0 in year one and 0.5 in years two and three. An additional associated Non-Standard Grant (NSG 5183969) of £6,418.00 for the purposes of the research will be paid upon presentation of invoices and can be used as follows: £1,027.00 – Learning & development costs £2,037.00 – User involvement costs £2,454.00 – Travel costs £900.00 – Miscellaneous costs Finally, the CI can apply for two individual grants (up to the combined value of £1000) within a calendar year. These can be used towards learning and development needs or to attend conferences. **Other support** The CI has access to a range of free resources from Macmillan such as booklets, leaflets and promotional materials. Macmillan offers a range of free face-to-face courses and e-learning, as well as conferences that are available to the CI. Finally, the CI has access to a wide network of support through other Macmillan professionals within the Midlands region and beyond.
University of Lincoln Nigel Horner, Head of School of Health and Social Care Email: nhorner@lincoln.ac.uk Tel: 01522 837443	**Financial support** The University of Lincoln financially contribute to the CI's salary with 0.5 in years two and three. Printing and other miscellaneous costs will be attributed to the University of Lincoln. **Other support** The CI will be based at the University of Lincoln, Brayford Campus and will receive

	support from a team of academic supervisors in the School of Health and Social Care, as well as within the MH2aSC (Mental Health, Health and Social Care) Research Group. In addition, a range of internal training courses and seminars will be available to support learning and development needs throughout the duration of the research. The CI is a registered PhD student at the University of Lincoln until 31st August 2019 and so will have access to University resources until that date.

ROLE OF FUNDER AND STUDY SPONSOR

Macmillan Cancer Support will be the primary funder for the study. They will contribute to the salary (1.0 in year one; 0.5 in years two and three) of the Chief Investigator, David Nelson from October 2015-October 2018. In addition to this, they have made provision and approved to fund a proportion of the research via a Non-Standard Grant (5183969) to the value of £6,418. Whilst funding for the research expires in October 2018, the Chief Investigator is registered as a full-time PhD student at the University of Lincoln until 31st August 2019.

The sponsor for the research will be the University of Lincoln. The University will take on responsibility for the initiation, management of and partial funding of the study (0.5 in years two and three). Furthermore, in line with HRA guidelines the University will accept responsibility for ensuring that the design of the study meets appropriate standards and that arrangements are in place to ensure appropriate conduct and reporting.

The University of Lincoln and Macmillan Cancer Support will work collaboratively throughout the research process. However, final decisions relating to the study design, conduct, data analysis and interpretation, manuscript writing and dissemination of results will rest with the sponsor and Chief Investigator.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

PhD Supervision

The Chief Investigator is a PhD student (until 31st August 2019) at the University of Lincoln. Therefore, the research process is overseen and quality assessed by a team of academic supervisors from the School of Health and Social Care. Meetings take place on a monthly basis. The team are as follows:

Dr Roslyn Kane, Reader in Health Care and Director of Studies for this PhD.

Dr Christine Jackson, Principal Research Fellow

Dr Ian McGonagle, Principal Lecturer

It is also the Chief Investigator's responsibility to produce and submit frequent progress reports to the supervisory team and administrative staff within the School. In addition, the Chief Investigator presents the progress of the research on an annual basis to other academics and peers within the School for review.

Research Steering Group

A Steering Group has been established to oversee the research process. They will meet three times a year for the duration of the research and have met twice already in 2016 (21st June and 11th October). Meetings are held at the University of Lincoln and focus on (but not exclusively), the research design, recruitment, data collection, analysis, and dissemination. Whilst the Chief Investigator will seek and take advice from the expert advisory panel, the final decisions will rest with him and the sponsor, as the research is being undertaken in fulfilment of a PhD.

The full list of Steering Group members can be found under key study contacts [insert page no. here] This includes academics with expertise in psycho-oncology and self-management, senior staff from Macmillan Cancer Support, a Lead Cancer Nurse and a patient representative.

Patient & Public Involvement

A patient representative who volunteered through Macmillan Cancer Support will sit on the Research Steering Group for the duration of the study. They will have the opportunity to comment on all aspects of the research process. A further three volunteers have been recruited through a local cancer support group. The research materials (covering letter, participant information sheet, questionnaire and consent form) have been piloted with all four patient representatives to gain feedback and suggested changes adopted where appropriate.

All participants will be given the opportunity to view the results of the study online via a web link (http://mhred.lincoln.ac.uk) on the participant information sheet. For those wanting a hard copy, this will be posted to them on behalf of the research team through the participating cancer centres.

Finally, the research team will work with key stakeholders and Macmillan Cancer Support staff to disseminate findings through local support groups in the Lincolnshire and Leicestershire area.

School of Health & Social Care Ethics Committee

The study has been reviewed internally and given a favourable opinion (12th February 2017) by the School of Health & Social Care Research Ethics Committee. The approval letter has been attached to the IRAS application.

Protocol contributors

The protocol has been completed by the Chief Investigator, David Nelson with contributions from the immediate research team at the University of Lincoln, who have commented on drafts of this document. In addition, the protocol has been reviewed by a senior academic outside of the immediate research team, Dr Paul Turner, Senior Lecturer at the University of Lincoln. Their comments and feedback have been adopted where appropriate. Finally, aspects of this protocol have been informed by Steering Group discussions and the research materials (cover letter, PIS, questionnaire, consent form) piloted with patient and public representatives.

The final decisions regarding the research process rests with the sponsor, the University of Lincoln and the Chief Investigator.

KEY WORDS: CANCER; SURVIVORSHIP; SELF-MANAGEMENT; PATIENT ACTIVATION; SELF-EFFICACY; RURAL; URBAN; MIXED METHODS

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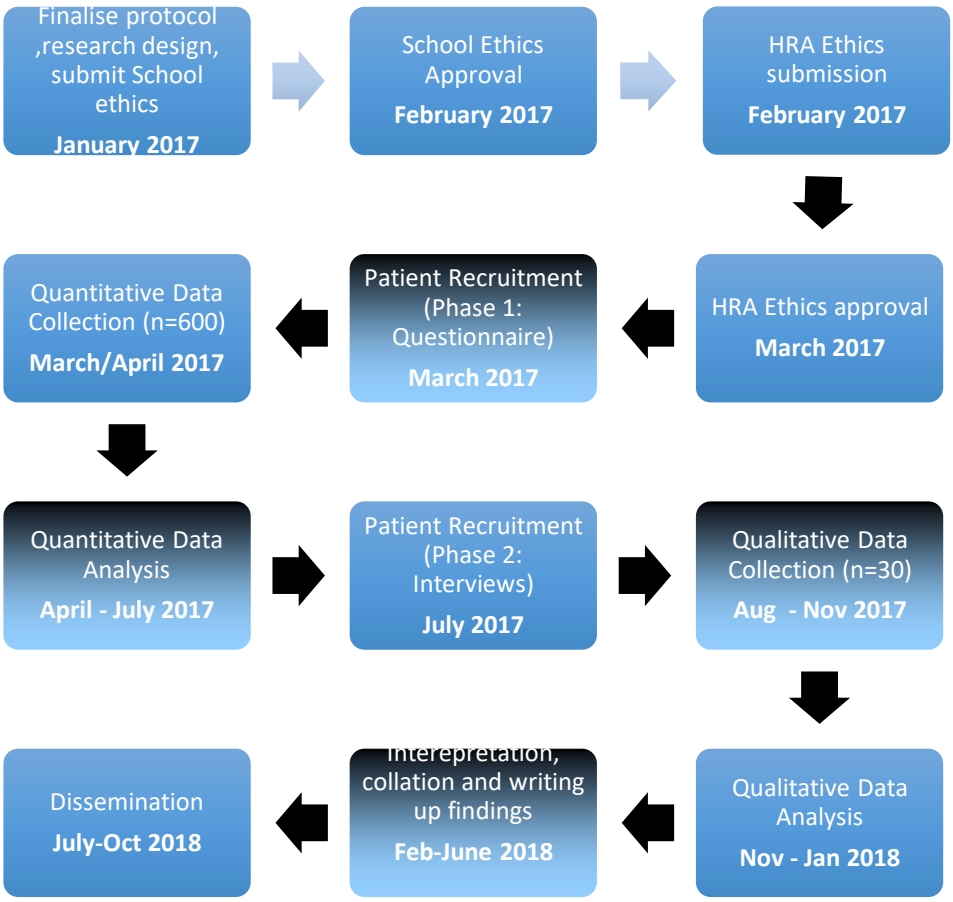
STUDY FLOW CHART

January 2017 - October 2018



STUDY PROTOCOL

Self-management in People Living with and Beyond Cancer in Rural and Urban Settings: A Comparative Mixed Methods Study.

1 BACKGROUND

There are two million people living with and beyond cancer in the UK and this is set to rise to 4 million by 2030 (Maddams et al, 2012). Whilst an increase in survivorship is a significant achievement to the advances in early detection and treatment of some cancers, it can have personal and economic implications for the patient, their family and the wider healthcare system. Evidence shows that many survivors have unmet needs particularly at the end of treatment, for example psychological needs and fear of recurrence (Armes et al, 2009).

The shift in thinking of cancer as an acute illness to a chronic one (Yaganti, 2015) has led to a growing body of work around self-management and people affected by cancer. Self-management in cancer survivorship has been defined as 'awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and well-being' (DH, Macmillan & NHS Improvement, 2010). In this context, to self-manage will involve managing the consequences of cancer and its treatment (physical, psychological, social practical problems), understanding how and when to seek support, recognising and reporting signs and symptoms of possible disease progression and making lifestyle changes to promote health, wellbeing and survival (Foster et al, 2015). Whilst the individual will be supported to self-manage, the onus rests on them to initiate contact with health professionals and other sources of support.

The increasing emphasis on self-management for people affected by cancer is situated within a policy context focusing on the increasing roles for, and responsibilities of, patients in managing and maintaining their health and wellbeing (NHS Improvement, Macmillan & DH, 2013). As a result, there has been an increasing number of self-management interventions to aid and encourage people affected by cancer to make decisions that will improve their health related behaviours and outcomes, by encouraging lay-led self-management skills (Gao & Yuan, 2011). Existing research (Shneerson et al, 2015) with cancer survivors has categorised self-management practices into the following six broad categories; support groups, diet, exercise, psychological therapies, complementary and alternative medicines, and spirituality and religious practices.

There is limited research examining whether living in a rural or urban area, has a significant bearing on a person's ability to manage their health following medical treatment. Furthermore, this is underexplored with people affected by cancer. The study builds on existing work in the field of self-management and cancer survivorship (Foster & Fenlon, 2011; Foster et al, 2015; Shneerson et al, 2015) by exploring and comparing self-management in cancer survivors from rural and urban settings. Existing studies (Burris & Andrykowski, 2010) have identified that people affected by cancer who reside in rural areas report greater anxiety and depressive symptoms, emotional problems and poorer mental functioning compared with those in non-rural areas. In addition, the need to travel for treatment causes many practical, emotional and financial problems (Butow et al, 2012). Whilst many factors in the rural setting can be detrimental to health, there are those that can promote health e.g. availability of outdoor recreation, peaceful and quiet environment (Winters et al, 2006).

The research will be undertaken to compare self-management in cancer survivors from a rural and urban setting. Participants will be recruited from an NHS cancer patient database in the East Midlands and will have completed primary treatment. Potential participants will be sent a self-completion postal questionnaire to explore differences in self-management amongst cancer survivors who reside in rural and urban areas. This should take approximately twenty minutes. This will be followed up with a series of face-to-face discussions that will explore the reasons why and how (if at all) people manage

their health following primary cancer treatment. The interviews will will take place in a private and convenient location and should last approximately sixty minutes.

The findings will be used to help support cancer survivors at a local and national level. They will increase our understanding of the influence of the rural and urban context of self-management. In addition the research will provide a more solid evidence base for providing tailored and appropriate support to people living with and beyond cancer. The results have the potential to inform future interventions, and ensure they are targeted and appropriate to the needs of cancer survivors in both rural and urban areas.

2 RATIONALE

The study builds on and contributes to work in the field of self-management and cancer survivorship (Foster & Fenlon, 2011; Foster et al, 2015; Shneerson et al, 2015). Existing studies (Burris & Andrykowski, 2010) have identified that people affected by cancer who reside in rural areas report greater anxiety and depressive symptoms, emotional problems and poorer mental functioning compared with those in non-rural areas. In addition, the need to travel for treatment causes many practical, emotional and financial problems (Butow et al, 2012). Despite this, there is limited research exploring whether living in a rural or urban area, has a significant bearing on a person's ability to manage their health following cancer treatment.

We seek to address this gap in the literature through recruiting study participants from the cancer patient database from two acute NHS trusts in the East Midlands. Participants will take part in a self-completion postal questionnaire. Following this, a sample of questionnaire respondents will be invited to discuss their experiences of managing their health at a face-to-face interview.

Firstly, the study will identify, and compare health promoting behaviours (physical activity, nutrition, interpersonal relationships, stress management, spiritual growth and health responsibility) amongst cancer survivors from rural and urban areas. This will also be explored in relation to other demographic and medical variables such as age, ethnicity and treatment type that existing research has found to be significantly associated with an increased use of self-management practices (Shneerson et al, 2015).

Secondly, we will explore patient activation in rural and urban cancer survivors. It can be defined as the skills, knowledge, and confidence to manage one's own health (Hibbard & Gilburt, 2014) and is considered a measure of one's self concept as a self-manager (Hibbard & Mahoney, 2010). Despite its increased use with UK populations and people with chronic illness, little is still known about its role in cancer survivorship (Mazanec et al, 2015).

Next, we seek to understand if there is a relationship between self-efficacy and where a cancer survivor lives. Self-efficacy is belief that one can successfully execute behaviour required to produce an expected outcome (Bandura, 1986). Recent research (Foster et al, 2015) has looked at this specifically in relation to cancer survivorship and self-management, and has found that confidence to self-manage problems faced after cancer treatment can vary widely depending on individual circumstance. Again we will compare this amongst those living in rural and urban areas.

Following the above, we will perform sub-group analyses on all measures to uncover any differences amongst demographic (eg: age, gender, religion, socio-economic status) and medical variables (eg: cancer type, treatment received, time since diagnosis). After this we will seek to understand if there is a relationship between self-management practices, patient activation, and self-efficacy in cancer survivors. Existing work with chronic disease patients suggests that those with higher activation practice more self-management behaviours (Hibbard et al, 2007).

Finally, we hope to identify and explore the barriers and facilitators to self-management in a rural and urban setting. This will be done through a series of qualitative discussions as an answer to this question requires a richer and in-depth method that only qualitative analyses would allow for. We will purposively select participants based on their answers to the above. For example, those who have high activation and high self-efficacy but are not engaging with self-management practices. These discussions will aim to explore the reasons for such a situation and to understand if geography acts as a barrier or facilitator to effective self-management.

3 CONCEPTUAL FRAMEWORK

The research draws on Foster and Fenlon's (2011) conceptual model of recovery of health and wellbeing following cancer treatment which recognises that social, physical and emotional factors all influence recovery. The model posits that people's subjective sense of health and wellbeing diminishes following the diagnosis and treatment of cancer and that this recovers over time. The model suggests that the extent to which health and wellbeing are affected and the rate at which they are restored will be affected by multiple factors such as the severity of the illness, its treatment and subsequent impact on physical health; and also pre-existing factors such as age, gender and social status of the individual affected. The way in which people cope with this and work to regain their health will depend on internal factors such as personality and self-efficacy to manage cancer related problems, and external factors, such as the support they have available to them.

4 RESEARCH QUESTION/AIM(S)

The study will be undertaken to (a) identify and compare health promoting behaviours in cancer survivors from a rural and urban setting (b) identify and compare patient activation in cancer survivors from a rural and urban setting (c) identify and compare self-management self-efficacy in cancer survivors from a rural and urban setting (d) to explore the relationship between self-management practices, patient activation and self-efficacy and (e) to identify, and explore, the barriers and facilitators to self-management in a rural and urban setting.

The study is a cross-sectional, mixed methods design incorporating two phases. Phase one consists of a quantitative self-completion survey collecting data on demographics, health promoting behaviours, patient activation and self-management self-efficacy (aims a-d). Phase two involves a series of qualitative interviews that aim to identify, and explore, the barriers and facilitators to self-management in rural and urban setting (aim e).

The specific research questions are as follows:

- RQ1: What are the differences in health promoting behaviours in cancer survivors from rural and urban areas?
- RQ2: What are the differences in patient activation in cancer survivors from rural and urban areas?
- RQ3: What are the differences in self-management self-efficacy in cancer survivors from rural and urban areas?
- RQ4: Is there a relationship between self-management practices, patient activation and self-efficacy?
- RQ5: What demographic variables are related to self-management practices, self-efficacy and patient activation?
- RQ6: What medical variables are related to self-management practices, self-efficacy and patient activation?

- RQ7: What are the barriers and facilitators to self-management in rural and urban areas and do they differ?

4.1 Objectives

The study's objectives are as follows:

- O1: To conduct a self-completion postal questionnaire with a sample of cancer survivors across the East Midlands.
- O2: To conduct a series of qualitative interviews with a sample of cancer survivors across the East Midlands.
- O3: To analyse and collate the findings from the quantitative and qualitative data.
- O4: To provide recommendations regarding future service delivery to suppprt self-management amongst cancer survivors.
- O5: To disseminate findings appropriately (PhD thesis, academic journals, conferences, Macmillan Cancer Support etc.)

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

An explanatory sequential mixed methods design will be used (Curry & Nunez-Smith, 2015). In this design, the quantitative phase is followed by a qualitative phase. The data collection and analysis for the quantitative component is completed first. The qualitative component is then implemented in order to generate further insights that may assist in explaining the quantitative findings. The qualitative data and their analysis refine and explain the quantitative results by exploring participants' views in more depth. Explanatory designs allow for purposeful may also be used when quantitative information is required in order to develop the sample for the qualitative phase. This approach often, though not always, uses a common sample (e.g. a purposeful sample is drawn from the larger sample used for the quantitative component). The data are integrated either through embedding or connecting.

Phase 1, a quantitative survey, provides an overall statistical picture of self-management practices, patient activation and self-efficacy amongst different groups of people living with and beyond cancer. This will allow sub-group analyses as well as exploring the relationship between different self-management outcome measures. Validated self-management outcome measures previously used with people affected by cancer will be used (Health Promoting Lifestyle Profile ii; PAM-13; Cancer Survivors Self-Efficacy Scale). The survey will ask participants for their post code, this will then be coded as rural or urban according to Office for National Statistics (ONS) classifications.

Access to the sample population will be sought through the Cancer Centre Manager at the collaborating NHS trusts (one in a predominantly rural setting and the other in a predominantly urban setting) who will act as gatekeepers to the study population. The Chief Investigator has met with both Cancer Centre Managers who have agreed to assist with recruitment for the research.

The study purpose, along with the inclusion and exclusion criteria [see page] will be explained to them and they will recruit on behalf of the research team (pending ethical approval) using their patient database. The research team will have no access to identifiable patient data. Staff at the Cancer Centre will confirm patient vital status (dead/alive) and ensure that participants have had a confirmed cancer diagnosis. All participants will be assigned a unique ID code to ensure anonymity and both trusts will cross check their list of patients to exclude any duplicates.

A sample size calculation (surveysystem.com) with a 95% confidence level and a margin of error of 4 determined a required sample size of 600. Conservatively assuming a response rate of 50% (in line

with similar research by Shneerson et al, 2015 in West Midlands), in the first instance, 1200 cancer survivors will be identified and sent a research pack. This will be evenly distributed amongst both NHS Trusts (600 invites each). Given 70% of Leicestershire's residents live in urban settlements (ONS, 2011 Rural/Urban Classifications) and in Lincolnshire 48% of the population reside in rural areas (ONS, 2011) and over half of the county's older people live in rural areas (ONS, 2011). Should the sample size not be reached, or we do not have enough urban or rural respondents for comparison, a further wave of invites will be sent out until this is reached. Patients will be selected at random from a list on the participating trusts database using a random number generator. The eligibility criteria will be checked against the inclusion/exclusion criteria by staff at the Cancer Centre. Random selection should seek to minimise bias in recruitment.

The research team will post hard copies of all research materials to both Cancer Centres. Staff at the collaborating trusts will confirm receipt via email or telephone to the Chief Investigator. Staff at the Cancer Centres will identify participants who meet the eligibility criteria and send them research materials by post (on behalf of the research team). This includes a letter of cover letter [Version 2.0; 160217], information sheet [Version 2.0; 160217], questionnaire [Version 2.0; 160217] and prepaid envelope for return to the research team. Space will be left on the invitation for the Cancer Centre to input the address of the patient at the top of the survey and for a unique ID code to be written in.

It will be made clear to potential participants on the information sheet that returning the survey implies informed consent. The Chief Investigator's contact details will be provided in case participants have any queries regarding the study. If no response is received within two weeks a reminder letter will be sent. If no response is received after a further two weeks, then the participant will not be contacted again.

Surveys will be coded upon receipt and SPSS software used to process and analyse the data. Descriptive statistics will be calculated with all variables to summarise the data. Relationships between variables will be measured using both parametric and non-parametric tests. T-tests will be used to assess whether there are significant differences in self-management outcomes (practices, activation, self-efficacy) between those in rural and urban areas. The correlation between self-management practices, activation and self-efficacy will be calculated.

The survey will give participants the opportunity to register their interest in the qualitative work by sending a reply slip with their contact details (name, phone no. and email) to the research team. This will be found at the end of the questionnaire. The Chief Investigator will separate these from the survey response upon receipt and store securely and separately, so as no participant can be identified.

Once all the questionnaire data has been returned, coded and analysed, the Chief Investigator will send a list of all patient ID codes to both cancer centres. Following this, medical data relating to primary cancer diagnosis, months since treatment, and types of treatment received will be collected from the patient database and sent to the research team. This ensures the research team have accurate and up to date data as well as not overburdening the respondent with a lengthy questionnaire. Respondents will be made aware of this on the questionnaire and can opt in or out through ticking a box.

Phase 2 will involve approximately 30 discussions with participants who have been purposively selected based on their survey responses. For example, those who have high activation and high self-efficacy but have low health-promoting behaviours. Participants will also be recruited to the qualitative work based on where they live (rural v urban) so as we can understand if geography acts as a barrier or facilitator to self-management. It is likely that not all participants who register their interest to be interviewed will be contacted, the PIS will explain this. ID codes will be checked against the eligibility criteria by Cancer Centre staff before making contact with participants for the qualitative interviews. The Chief Investigator will make contact with participants via their preferred method

(email or telephone as indicated on the reply slip) and will arrange a convenient time and location for interview. This is likely to be at a convenient community location or in their home should they consent to this. Telephone interviews will also be offered for those who would prefer this method.

Written informed consent will be obtained prior to interview via consent form (Version 2.0; 16/02/17) and the CI will go through the PIS with the participant prior to interview. Interviews will last approximately 60 minutes and will be digitally recorded and transcribed by the Chief Investigator. During transcription, pseudonyms will be used for all participants. The Chief Investigator will take responsibility for ensuring these are consistent and used throughout. All data from the interviews will be transcribed verbatim and analysed using the Computer Aided Qualitative Data Analysis Software (CAQDAS) NVivo. The data will be analysed thematically (Braun & Clarke, 2006). The findings will then be used to understand the reasons behind why different groups manage their health in different ways and whether where they live enables or hinders them from doing so.

All physical and digital data will be stored securely at the University of Lincoln, Brayford campus in the Chief Investigators office which will remain locked when not in use. The Chief Investigator will take responsibility as the long-term custodian of the data.

6 STUDY SETTING

Preliminary desk based research and administrative support throughout the project will be conducted at the University of Lincoln by the Chief Investigator.

The Cancer Centre at both United Lincolnshire Hospitals NHS Trust and University Hospitals of Leicester NHS Trust will recruit participants by sending the research materials on behalf of the research team. They will identify participants through patient records for possible participation in the research, send the research materials on behalf of the research team but the research will take place elsewhere.

Questionnaires will be sent to participants' home address and likely completed there also. Responses will be sent to the research team at the University of Lincoln. The Chief Investigator will collect and analyse the quantitative data in their personal office on campus.

Interviews will be held at a convenient time and location for the participant (eg: their home, community location) in Lincolnshire and Leicestershire. Telephone interviews will also be offered for those who would prefer this method. Interviews will be arranged on a case by case basis and the Chief Investigator will work with participants to ensure arrangements are in place and that a comfortable and appropriate location is used. Qualitative data will be transcribed and analysed at the University of Lincoln.

Finally, findings from both the quantitative and qualitative work will be analysed, collated and written up at the University of Lincoln.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

The study population is people who have had a diagnosis of cancer and have undergone primary treatment who are registered on the patient database at either United Lincolnshire Hospitals NHS Trust and University Hospitals of Leicester NHS Trust. The population has not been refined to any specific cancer type, in order to be as inclusive as possible and to account for differences in the patient pathway.

Whilst we aim to be as inclusive as possible, time and financial constraints on the project mean we cannot offer the services of a translator or interpreter.

Participants will be recruited to both phases of the study according to the below inclusion/exclusion criteria.

7.1.1 Inclusion criteria

- Participants must be 18 years or older.
- Participants must have had a confirmed primary diagnosis of cancer.
- Participants must be willing and able to provide informed consent.
- Participants must have undergone primary cancer treatment within the last five years
- Participants must be registered at either United Lincolnshire Hospitals NHS Trust or University Hospitals of Leicester NHS Trust
- Participants must have a good command of the English language (for quant and qual work) and an adequate level of hearing (for qual work).

7.1.2 Exclusion criteria

- Participants under 18 years of age.
- Participants with any clinical, histological or radiological evidence of metastatic spread/local recurrence of disease.
- Participants who have started active oncology treatment within the last 12 months.
- Patients who were treated more than five years ago.
- Participants being treated for best supportive care.
- Participants who do not have an adequate level of spoken or written English.

7.2 Sampling

A sample size calculation (surveysystem.com) with a 95% confidence level and a margin of error of 4 determined a required sample size of 600. Conservatively assuming a response rate of 50% (in line with similar research by Shneerson et al, 2015 in West Midlands with cancer survivors), in the first instance, 1200 cancer survivors will be identified and sent a research pack. This will be evenly distributed amongst both NHS Trusts (600 invites each). Given 70% of Leicestershire's residents live in urban settlements (ONS, 2011 Rural/Urban Classifications) and in Lincolnshire 48% of the population reside in rural areas (ONS, 2011) and over half of the county's older people live in rural areas (ONS, 2011). Should the sample size not be reached, or we do not have enough urban or rural respondents for comparison, a further wave of invites will be sent out until this is reached. Patients will be selected at random from a list on the participating trusts database usisng a random number generator. The eligibility criteria will be checked against the inclusion/exclusion criteria by staff at the Cancer Centre. Random selection should seek to minimise bias in recruitment.

For the qualitative work, our sample size is informed by similar qualitative studies with cancer populations (Henshall et al, 2016). Therefore, our estimated required sample is 30, however, we will sample until we reach data saturation.

7.3 Recruitment

Participants will be recruited via staff at the participating Cancer Centres (United Lincolnshire Hospitals NHS Trust & University Hospitals of Leicester NHS Trust).

Both Cancer Centre Managers have been briefed on the participant eligibility criteria and have confirmed that they can identify and recruit potential participants according to this. They have been provided with a hard copy and will use this when drawing the sample from their patient database.

Following the survey but prior to the qualitative work, staff at both Cancer Centres will again need to screen the unique patient ID codes against their database to ensure that participants continue to meet the eligibility criteria. The research team will provide the ID codes to both Cancer Centres before making contact with potential participants for interview.

7.3.1 Sample identification

Participants will be identified by staff at the participating Cancer Centres under supervision by the Cancer Centre Manager (Charles Carroll, ULHT; Sarah Morley, UHL). Staff will have access to, and training in, the use of the patient database (InfoFlex and Somerset) given their employment by the trust at one of the participating Cancer Centres. Initially, this will involve knowledge of the database system to refine according to the eligibility criteria. The database does not contain any personal information such as name or address. Therefore, the patients NHS number on the cancer patient database will be cross checked with the Patient Admin System (PAS) to obtain the name and address of the patient. PAS will also be used to confirm if the patient is dead or alive.

7.3.2 Consent

Participants will be provided with an information sheet giving an overview of the study and what it would involve. The information sheet will explain that returning the questionnaire implies informed consent.

Full identification of the immediate research team (David Nelson, Ros Kane, Ian Mcgonagle, Christine Jackson) and funders (Macmillan Cancer Support) for the study will be provided on the information sheet. In addition to this contact details will be provided for future contacts (Chief Investigator, R&D, Macmillan Cancer Support, and Chair of School Ethics Committee).

Participants will be assured on the cover letter, information sheet, questionnaire and consent form that participation is voluntary and that they have the right to withdraw at any time without their rights and/or care being affected.

Participants will be assured on the cover letter, information sheet, questionnaire and consent form that their responses will be treated confidentially.

Further to the above, the CI will take written informed consent (via a consent form) to digitally record the qualitative discussions prior to the interview taking place. This will be signed by the CI and the participant. The CI will bring two copies of the consent form (one for the researcher and one for the respondent to keep).

8 ETHICAL AND REGULATORY CONSIDERATIONS

Ethical approval will be sought from the NHS Health Research Authority (HRA) via the online Integrated Research Application System (IRAS) with the appropriate supporting documentation. In addition to

this, the study has been reviewed and given a favourable opinion by the University of Lincoln School of Health and Social Care Ethics Committee on 12th February 2017.

Participants will be made aware that participation is completely voluntary (on the cover letter, information sheet, questionnaire and consent form). However, the research materials will explain that once data analysis has commenced for the quantitative work (expected summer 2017 as explained on the PIS) and for the qualitative work (expected winter 2017 as explained on the interview consent sheet) that it is not possible to remove individual data as these are anonymised. Should participants wish to find out further information about the study prior to participation they can contact the research team directly via the contact details on the information sheet. In addition to this if they have a problem or wish to make a complaint they can contact the Chair of the School ethics committee or their local R&D office (also found on the information sheet).

There is a risk that participants may become distressed when filling out the questionnaire or when discussing their cancer experience at interview. The information sheet will have the contact details of local cancer support services in Lincolnshire and Leicestershire, should they require it. Furthermore, the CI has demonstrable experience conducting research with people affected by cancer and has recently attended a Macmillan Cancer Support SAGE and THYME (November 2016) workshop on coping with patients in distress.

It is unlikely that criminal or other disclosures would occur during the research. However, there is a small chance this could occur during the qualitative interviews. Should this occur the participant will have to sign a consent form saying that they understand that if they disclose anything illegal, unethical, or indicates that someone is/has been put at risk, the research team will inform the appropriate authority.

Participants will be ensured that all data (electronic and paper) will be stored in a locked metal filing cabinet at the University of Lincoln, Brayford Campus. This will be stored in line with the MH2aSC research group policy for five years and then destroyed (e-copies deleted and paper copies shredded). Only the immediate research team (David Nelson, Ros Kane, Ian McGonagle and Christine Jackson) will have access to patient data.

Participants will be made aware (on the PIS, questionnaire and consent form) that by completing and returning the questionnaire, they are giving their consent for the research team to have access to their relevant health information for the purposes of the study. For example, their cancer diagnosis, treatment received, time since treatment began, time since diagnosis).

In addition, participants will be made aware (on the PIS, questionnaire and consent form) that by completing and returning the questionnaire, they are giving their consent for the information provided to be used in future research studies (where appropriate) and shared anonymously with internal and external partners (e.g.: Steering Group members, Macmillan Cancer Support) where appropriate. Survey responses will be allocated a unique ID code (by Cancer Centre staff) to ensure that participants remain anonymous. The CI will take responsibility for ensuring that all data is anonymised and that consistent pseudonyms are used in the qualitative data.

Should participants register their interest in the qualitative work, they will be reassured on the information sheet and on the further contact slip that their name and contact details will be stored separately and securely from their questionnaire response.

Potential risks for the researchers themselves

The CI will adhere to the University of Lincoln's Lone Working Policy.

The study involves interviews with participants across the East Midlands so there will be travel involved. As a safety measure the CI will maintain frequent contact with other members of the research team when out in the field. This will be done via telephone or text message.

Identification/Recruitment of potential participants

The research team will not identify potential participants or rweview personal information of patients. This will be done via sdtagg at the participating Cancer Centre's at United Lincolnshire Hospitals NHS Trust and University Hospitals of Leicester NHS Trust who have access to a cancer patient database (Infoflex and Somerset). Whilst the database does not contain any identifiable personal information, the patients NHS number will need cross checked with the Patient Administartion Syetem (PAS) to obtain the participants address and to confirm that the patient is still alive. This will be done by staff at the trust and not the research team.

The covering letter will state that the trust are contacting the participant on behalf of the research team, as they do not pass on participants personal details without their consent.

8.2 Research Ethics Committee (REC) review & reports

Before the start of the study, approval will be sought from the NHS HRA and will be reviewed by a REC. The study has already been approved by the School of Health & Social Care ethics committee on the 12th February 2017.

Substantial amendment that require review by REC will not be implemented until the REC grants a favourable opinion for the study. In addition, all substantial amendments will be logged with the participating R&D departments (United Lincolnshire Hospitals NHS Trust & University Hospitals of Leicester NHS Trust).

All correspondence with the REC will be retained. An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended. If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination. It is the Chief Investigator's responsibility to produce annual reports as required and they will notify the REC of the end of the study. Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

8.3 Peer review

The study has been reviewed (and given a favourable opinion) by the University of Lincoln's School of Health and Social Care Research Ethics Committee (consisting of senior academics and members of the public external to this study).

An expert Steering Group has been set up to advise and monitor the progress of the research. The group will meet three times a year and has met twice already in 2016.The group contains academics with expertise in cancer survivorship and self-management research,as well as clinical oncology staff, senior staff from Macmillan Cancer Support and a patient representative. Aspects of this protocol have been discussed and informed by Steering Group discussions.

Finally, the CI is a PhD student, therefore the whole research process will be overseen and the quality assessed by a team of trained academic supervisors at the University of Lincoln. It is also the CI's responsibility to produce and submit frequent progress reports to the supervisory team and

administrative staff within the School of Health & Social Care. In addition, the CI also presents the progress of the research on an annual basis to other academics and peers within the School for review.

8.4 Patient & Public Involvement

A patient representative who volunteered through Macmillan Cancer Support will sit on the Research Steering Group for the duration of the study. They will have the opportunity to comment on all aspects of the research process. A further three volunteers have been recruited through a local cancer support group. The research materials (covering letter, participant information sheet, questionnaire and consent form) have been piloted with all four patient representatives to gain feedback and suggested changes adopted where appropriate.

All participants will be given the opportunity to view the results of the study online via a web link (http://mhred.lincoln.ac.uk) on the participant information sheet. For those wanting a hard copy, this will be posted to them on behalf of the research team through the participating cancer centres.

Finally, the research team will work with key stakeholders and Macmillan Cancer Support staff to disseminate findings through local support groups in the Lincolnshire and Leicestershire area.

8.5 Regulatory Compliance

Before any site can enrol patients into the study, the Chief Investigator will apply for NHS permission from the site management organisation, HEI or NHS Research & Development (R&D).

For any amendment that will potentially affect a site's NHS permission, the Chief Investigator or designee will confirm with that site's R&D department that NHS permission is ongoing (note that both substantial amendments, and amendments considered to be non-substantial for the purposes of REC may still need to be notified to NHS R&D).

8.6 Protocol compliance

The Chief Investigator and immediate research team (RK, IMG, CJ) will monitor compliance with the protocol and report any deviations. It should be recognised that accidental protocol deviations can happen at any time. They must be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

8.7 Data protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles.

Physical data will be stored in a locked metal filing metal cabinet at the office of the Chief Investigator at the University of Lincoln, Brayford campus. The office will be locked when not in use. Physical data will only be made accessible to the immediate research team (RK, IMG, CJ). Survey respondents who wish to register their interest in the qualitative work via the reply slip will have their name and contact details stored separately from their questionnaire response. This will again be in a locked filing cabinet that is only accessible to the immediate research team.

Digital data will be encrypted and stored on a password protected PC that will only be accessible to the research team. This will again be in the office of the Chief Investigator at the University of Lincoln, Brayford campus. As before the office will be locked when not in use.

Data will be analysed at the University of Lincoln. The Chief Investigator will ensure that all data is anonymised (ID codes, pseudonyms used etc.) prior to sharing with the research team. Data will only be transferred internally amongst the immediate research team. Data for participant's activation scores will be shared with Insignia Health Ltd. who own the copyright to the PAM-13 measure. This will contain no information that could identify any of the participants. No published data will include anything that could identify the research participants.

The Chief Investigator will act as the long term custodian for the data generated by the study. The data will be stored for five years following completion of the research then destroyed. In the event of the Chief Investigator leaving the host institution, the wider research team will take responsibility for the long term storage and security of the data.

Please see University of Lincoln's Mental Health, Health and Social Care (MH_2aSC) Research Group's Data Management Policy that will be adhered to for the duration of the research.

8.8 Indemnity

Please see letter [attached to IRAS application] confirming the University of Lincoln's (the sponsor) Employer Liability, Public Liability, and Professional Indemnity Insurance. Aon Ltd. are insurance brokers on behalf of the University of Lincoln. The policies have been renewed on the 1 August 2016 and are in force for a further 12 months until 1 August 2017.

8.9 Amendments

The Chief Investigator and University of Lincoln research team will take responsibility for decisions to amend the protocol and for deciding whether an amendment is substantial or non-substantial. All correspondence with the REC will be stored by the Chief Investigator and study sponsor.

If the Chief Investigator or sponsor wishes to make a substantial amendment to the REC application or the supporting documents, they must submit a valid notice of amendment to the REC for consideration. The REC will provide a response regarding the amendment within 35 days of receipt of the notice. It is the sponsor's responsibility to decide whether an amendment is substantial or non-substantial for the purposes of submission to the REC. Following a response from the REC, the Chief Investigator will take responsibility for updating the study protocol, maintaining a record of amendments and updating the protocol version and research numbers (information sheet, consent forms etc.) where appropriate.

Amendments will also be registered with the participating NHS R&D departments to assess whether the amendment affects the NHS permission for that site. Note that some amendments that may be considered to be non-substantial for the purposes of REC and/or MHRA may still need to be notified to NHS R&D (e.g. a change to the funding arrangements). For studies with English sites processed in NIHR CSP the amendment should be submitted in IRAS to the lead CRN, which will determine whether the amendment requires notification to English sites or may be implemented immediately (subject to REC approval were necessary).

8.10 Access to the final study dataset

The Chief Investigator, immediate research team (RK, IMG, CJ) and where necessary, members of the Steering Group will have access to the final dataset. That is, the quantitative SPSS data file and the qualitative NVivo project file consisting of the coded interview transcripts. All parties will ensure that overall results are not disclosed prior to the main publications (Final Report and PhD thesis).

The Patient Activation scores will be shared with Insignia Health Ltd. who granted permission to use the PAM-13 measure, on the condition that anonymised data is shared with them upon completion of the research.

Given the broad scope of the research, there is potential that data could be used for future analyses outside the remit of this study or for secondary analysis. Participants will be made aware of this on the information sheet, questionnaire and consent form. Should anyone request the use of the dataset, they will have to submit a written formal request that will be reviewed by the Steering Group. The research team will have the final decision as to whether approval is granted.

9 DISSEMINATION POLICY

9.1 Dissemination policy

Final data arising from the study will be owned by the University of Lincoln.

On completion of the study, the data will be analysed, collated, and a Final Study Report (due late summer 2018) presented and made available to the primary funder, Macmillan Cancer Support.

This full study report will be made accessible on the University of Lincoln's Institutional Repository (http://eprints.lincoln.ac.uk.), a research resource for the permanent deposit of research outputs produced by University of Lincoln staff and students.

The rights to publish any of the study data will rest with the Chief Investigator, the research team and Macmillan Cancer Support.

Macmillan Cancer Support and the University of Lincoln will be acknowledged within all study outputs as the funders of the research.

There are plans to notify the participants of the research findings. Following completion of the Final Study Report, a summary of the results will be available online via a web link (http://mhred.lincoln.ac.uk) that will be made available to participants on the information sheet. They will be made aware on the information sheet that it will be several months before the results are available. In addition to this, the questionnaire will give participants the opportunity to request a paper copy of the key study findings that will be posted to them at the end of the research.

In addition to the above, the outcomes of the research will be disseminated locally in conjunction with Macmillan Cancer Support, as well as through appropriate academic journals and national and/or international conferences.

9.2 Authorship eligibility guidelines and any intended use of professional writers

Upon completion of the research, a Final Study Report of the results and major outcomes of the study will be completed for the primary funder, Macmillan Cancer Support. This will be written by the Chief Investigator and immediate research team (RK, CJ, IMG).

Following this, the Chief Investigator will write up the entire study in the form of a PhD thesis. They will receive support from a team of academic supervisors in completing this but they alone will be the author on the final thesis.

There will be potential for any subsequent outputs (journal articles, reports, conference papers and presentations etc.) to be co-authored with the immediate research team and members of the Steering Group.

The research team will not use the services of any professional writers.

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11. APPENDICIES

11.1 Appendix 1- List of supporting documentation (submitted to HRA via IRAS).

Required documentation	Further information	Version Number	Date
IRAS form	Completed IRAS form to be sent to the HRA for review.	Project ID: 204679	
Sponsor Insurance and Indemnity	University of Lincoln Sponsor insurance and indemnity.		29/07/16
Summary CV for Supervisor	Summary CV for Dr Ros Kane.		21/11/16
Summary CV for Chief Investigator	Summary CV for David Nelson.		21/11/16
Cover Letter for Study	Cover Letter from NHS Trust to be sent to participants	2.0.	16/02/17
Participant information sheet (PIS)	Participant information sheet that will be sent to potential participants alongside the covering letter and questionnaire.	2.0.	16/02/17
Validated Questionnaire	Questionnaire that will be sent to potential participants	2.0.	16/02/17
Reminder Letter	Reminder letter sent to participants if no response received within two weeks.	2.0.	16/02/17
Further Contact Slip	Reply slip for participant to register their details to take part in phase 2 (qualitative interviews)	2.0.	16/02/17

Participant consent form	Participant consent form to be used in the qualitative interviews.	2.0.	16/02/17
Research protocol	The protocol provides a detailed overview of the study.	1.0.	16/02/17
Letter from funder	Letter from Macmillan cancer Support		26/10/16
Letter from sponsor	Letter from University of Lincoln		10/12/16
University of Lincoln School of Health and Social Care Ethics Committee Approval	Approval letter from local ethics committee.		12/02/17
Statement of Activities – recruiting site	Statement of Activities for ULHT.	1.0.	21/02/17
Statement of Activities – recruiting site	Statement of Activities for UHL	1.0.	21/02/17
Schedule of Events – recruiting site	Schedule of Events for ULHT	1.0.	21/02/17
Schedule of Events – recruiting site	Schedule of Events for UHL.	1.0.	21/02/17
Data Management Policy	MH2aSC Research group data management policy.	1.0.	01/10/16

APPENDIX 8: SCHOOL OF HEALTH AND SOCIAL CARE ETHICAL APPROVAL

UNIVERSITY OF LINCOLN

David Nelson
School of Health and Social Care
Bridge House
University of Lincoln LN6 7TS

12 February 2017

Dear David

Self-management in people living with and beyond cancer in a rural and urban setting: a comparative mixed methods study, submission to HSC Ethics Committee

Thank you for your resubmission for ethical approval for the above study. I am pleased to confirm the HSC Ethics Committee's approval for your study.

This is a much-needed piece of research and we are delighted with your attention to detail and commitment to high quality research. We would like to take the opportunity to wish you and your team every success with this study.

Yours sincerely,

Leslie Hicks

Dr Leslie Hicks
Co-Chair, School of Health and Social Care Ethics Committee

APPENDIX 9: NHS RESEARCH ETHICS COMMITTEE (REC) VALIDATION LETTER

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Mr David Nelson
Macmillan Research Fellow
University of Lincoln
School of Health & Social Care
Bridge House, Brayford Pool
Lincoln
LN6 7TS

West of Scotland REC 4
West Ambulatory Care Hospital
Dalnair Street
Yorkhill
Glasgow
www.nhsggc.org.uk

Date 24 February 2017
Direct line 0141-232-1806
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Mr Nelson

Study title: **Self-Management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study**
REC reference: **17/WS/0054**
Protocol number: **280755**
IRAS project ID: **204679**

Thank you for your application for ethical review, which was received in full on 23 February 2017. I can confirm that the application is valid and will be reviewed by the Proportionate Review Sub-Committee on 10 March 2017.

One of the REC members is appointed as the lead reviewer for each application reviewed by the Sub-Committee. I will let you know the name of the lead reviewer for your application as soon as this is known.

Please note that the lead reviewer may wish to contact you by phone or email between 24 February 2017 to 10 March 2017 to clarify any points that might be raised by members and assist the Sub-Committee in reaching a decision.

If you will not be available between these dates, you are welcome to nominate another key investigator or a representative of the study sponsor who would be able to respond to the lead reviewer's queries on your behalf. If this is your preferred option, please identify this person to us and ensure we have their contact details.

You are not required to attend a meeting of the Proportionate Review Sub-Committee.

Please do not send any further documentation or revised documentation prior to the review unless requested.

Documents received

The documents to be reviewed are as follows:

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [UofL Ethics Approval]		12 February 2017
Covering letter on headed paper [Covering Letter]	1	21 February 2017

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Topic guide]	1	23 February 2017
IRAS Application Form [IRAS_Form_22022017]		22 February 2017
Letter from funder [Letter from Macmillan Cancer Support]		26 October 2016
Letter from sponsor [Letter from sponsor]		10 December 2016
Letters of invitation to participant [Invite/Cover Letter NHS Trust]	2	16 February 2017
Other [Further Contact Slip]	2	16 February 2017
Other [Reminder Letter]	2	16 February 2017
Other [MH2aSC Data Management Policy]		
Participant consent form [Consent form - qual interviews]	2	16 February 2017
Participant information sheet (PIS) [PIS]	2	16 February 2017
Research protocol or project proposal [Protocol]	1	21 February 2017
Summary CV for Chief Investigator (CI) [CV_DNelson]		21 November 2017
Summary CV for supervisor (student research) [Supervisor_CV_RKane]		21 November 2016
Validated questionnaire [Questionnaire]	2	16 February 2017

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

Notification of the Sub-Committee's decision

We aim to notify the outcome of the Sub-Committee review to you in writing within 21 calendar days from the date of receipt of a valid application.

If the Sub-Committee is unable to give an opinion because the application raises material ethical issues requiring further discussion at a full meeting of a Research Ethics Committee, your application will be referred for review to the next available meeting. We will contact you to explain the arrangements for further review and check they are convenient for you. You will be notified of the final decision within 60 days of the date on which we originally received your application. If the first available meeting date offered to you is not suitable, you may request review by another REC. In this case the 60 day clock would be stopped and restarted from the closing date for applications submitted to that REC.

Setting up sites in the NHS

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should work with the relevant care organisation to ensure management permission is confirmed before the study begins. Guidance on how to work with sites is provided in the IRAS help section at https://www.myresearchproject.org.uk/help/hlpnhshscr.aspx

Final management permission will not be confirmed until after a favourable opinion has been given by this Committee, and all other relevant approvals for the research to begin are in place. Please contact the NHS R&D office at the lead site in the first instance for further guidance.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor. It will be your responsibility to ensure that other investigators, research

collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/WS/0054	**Please quote this number on all correspondence**

Yours sincerely

Miss Sophie Bagnall
Assistant Coordinator

Copy to: *Mr Nigel Horner*

APPENDIX 10: NHS RESEARCH ETHICS COMMITTEE (REC) APPROVAL

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Mr David Nelson
Macmillan Research Fellow
University of Lincoln
School of Health & Social Care
Bridge House, Brayford Pool
Lincoln
LN6 7TS

West of Scotland REC 4
West Ambulatory Care Hospital
Dalnair Street
Yorkhill
Glasgow
www.nhsggc.org.uk

Date 24 April 2017
Direct line 0141-232-1806
e-mail Wosrec4@ggc.scot.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Dear Mr Nelson

Study title: **Self-Management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study**
REC reference: **17/WS/0054**
Protocol number: **280755**
IRAS project ID: **204679**

Thank you for your letter of 10 April 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

- In the updated Letter of Invitation to participant the section that has been added at the end of the letter should be updated to read as;

Every effort has been made to ensure that this questionnaire has been sent to the appropriate patient population through checking of patient databases. If you have recently experienced a recurrence of cancer or are unwell for any other reason and feel you would be unable to take part in this research please accept our apologies for sending this letter to you.

For general support you can contact Macmillan Cancer Support on Freephone 0808 808 00 00 or via their website macmillan.org.uk.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the

procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [UofL Ethics Approval]		12 February 2017
Covering letter on headed paper [Covering Letter]	1	21 February 2017
Interview schedules or topic guides for participants [Topic guide]	1	23 February 2017
IRAS Application Form [IRAS_Form_22022017]		22 February 2017
Letter from funder [Letter from Macmillan Cancer Support]		26 October 2016
Letter from sponsor [Letter from sponsor]		10 December 2016
Letter from statistician [Letter from Statistician - Dr Paul Turner, Uni of Lincoln]		03 April 2017
Letters of invitation to participant [Invite/Cover Letter NHS Trust]	2.1	20 March 2017
Other [MH2aSC Data Management Policy]		
Other [Further Contact Slip]	2.1	20 March 2017

Document	*Version*	*Date*
Other [Response to Sub-Commitee]	1	04 April 2017
Participant consent form [Consent form - qual interviews]	2	16 February 2017
Participant information sheet (PIS) [PIS]	2.1	20 March 2017
Research protocol or project proposal [Protocol]	1	21 February 2017
Summary CV for Chief Investigator (CI) [CV_DNelson]		21 November 2017
Summary CV for supervisor (student research) [Supervisor_CV_RKane]		21 November 2016
Validated questionnaire [Questionnaire]	2	16 February 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/WS/0054	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Alternate Vice Chair
Dr Michael Fail

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Mr Nigel Horner*

APPENDIX 11: HEALTH RESEARCH AUTHORITY (HRA) APPROVAL

NHS
Health Research Authority

Mr David Nelson
Macmillan Research Fellow
University of Lincoln
School of Health & Social Care
Bridge House, Brayford Pool
Lincoln
LN6 7TS

Email: hra.approval@nhs.net

25 April 2017

Dear Mr Nelson

Letter of HRA Approval

Study title:	**Self-Management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study**
IRAS project ID:	**204679**
Protocol number:	**280755**
REC reference:	**17/WS/0054**
Sponsor	**University of Lincoln**

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	204679

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **204679**. Please quote this on all correspondence.

Yours sincerely

Miss Lauren Allen
Assessor

Email: hra.approval@nhs.net

Copy to: *Mr Nigel Horner (Sponsor contact)*

APPENDIX 12: UNITED LINCOLNSHIRE NHS TRUST (ULHT) R&D APPROVAL

United Lincolnshire Hospitals NHS
NHS Trust

RESEARCH & DEVELOPMENT DEPARTMENT

Contact: Jasmine Fawcett
T: 01522 512512 ext 582923
F: 01522 597845 Email: Jasmine.Fawcett@ULH.nhs.uk

Lincoln County Hospital
Greetwell Road
Lincoln
LN2 5QY

David Nelson
Macmillan Research Fellow
University of Lincoln
School of Health and Social Care
Brayford Pool
Lincoln. LN6 7TS

Date: 8th May 2017
R&D Ref: 181016Nelson
REC Ref: 17/WS/0054

Dear David,

Re: Self-Management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study (IRAS ID 204679)

I am pleased to confirm that with effect from the date of this letter, the above study has Trust Research & Development authorisation to commence at United Lincolnshire Hospitals NHS Trust. The research must be conducted in line with the Protocol and fulfil any contractual obligations agreed. If you identify any issues during the course of your research that are likely to affect these obligations you must contact the R&D Office as soon as possible.

In order for the United Lincolnshire Hospitals NHS Trust to comply with targets set by the Department of Health through the 'Plan for Growth', there is an expectation that the first participant will be recruited within 70 days of receipt of a Valid Application. **It is essential that you notify the ULHT Research Team as soon as you have recruited your first participant to the study, and ensure that the date is recorded on the EDGE Database by your local EDGE User.**

If we have not heard from you within the specified time period we will contact you not only to collect the data, but also to record any issues that may have arisen to prevent you from achieving this target. It is essential that you get in touch with us if there is likely to be a problem in achieving this target so that we can discuss potential solutions. The Trust is contractually obliged to meet the 70 day target and if an adequate reason acceptable to the NIHR has not been submitted to explain the issues preventing the recruitment of your first participant, the Trust will be financially penalised. In addition, we are required to publish the Title, REC Reference number, local target recruitment and actual recruitment as well as 70 days data for this study on a quarterly basis on the ULHT public accessed website.

Undertaking research in the NHS comes with a range of regulatory responsibilities. Please ensure that you and your research team are familiar with, and understand the roles and responsibilities both collectively and individually.

It is important that you familiarise yourself with the Standard Operating Procedures, Policies and all other relevant documents which can be located by visiting https://www.ulh.nhs.uk/about/training-and-research/research-and-development.

United Lincolnshire Hospitals NHS
NHS Trust

The R&D Office is keen to support and facilitate research where ever possible. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office.

On behalf of the Trust, I wish you every success with the study.

Yours sincerely,

Professor Tanweer Ahmed, MBA, FICR
Director of Lincolnshire Clinical Research Facility, Interim Joint Director of Research & Development & IP Lead

Cc.
Helen Ayre (Research Manager)
Angela Dillon (Edge Administrator)
Charles Carroll (Cancer Centre Manager, ULHT)

This Trust actively supports clinical research
Help us, help you by getting involved!

APPENDIX 13: UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST (UHL) R&I APPROVAL

From: Wann Lisa - Research and Innovation Manager
To: Morley Sarah - Deputy Head of Performance - Cancer
Cc: Glab Agnieszka - Research Support Officer; Nicholson Sarah - R&D Manager; David Nelson; Nigel Horner; Branson Amy - Senior Study Support Officer
Subject: RE: EDGE ID 88300 / IRAS 204679 - TITLE Self-Management in People Living with and Beyond Cancer (LWABC) in Rural and Urban Settings: A Comparative Mixed Methods Study
Date: 07 August 2017 17:13:57

Attachments: Microsoft Word - Ver_1 0_statement-activities-UHL_IRAS_204679_070817.pdf

Dear Sarah,

I am pleased to confirm that the University Hospitals of Leicester NHS Trust has the capacity and capability to deliver the above research activity in accordance with the **Statement of Activity / Schedule of Events and Protocol** provided. The research must be conducted in line with the Protocol and fulfil any contractual obligations agreed. If you identify any issues during the course of your research that are likely to affect these obligations you must contact the R&I Office as soon as possible. UHL is a PIC site for this research.

Please note that you may need to wait to commence recruitment until your Sponsor issues a Green Light to commence. You must liaise with your Sponsor to confirm agreement that you may commence activity before you start.

Undertaking research in the NHS comes with a range of regulatory responsibilities. Please ensure that you and your research team are familiar with, and understand the roles and responsibilities both collectively and individually.

Documents listing the roles and responsibilities for all individuals involved in research can be found on the R&I pages of the Public Website. It is important that you familiarise yourself with the Standard Operating Procedures, Policies and all other relevant documents which can be located by visiting http://www.leicestersresearch.nhs.uk/standard-operating-procedures/

Document	Version	Date
Letters of invitation to participant [Invite/Cover Letter NHS Trust]	2.1	20-Mar-17
Participant information sheet (PIS) [PIS]	2.1	20-Mar-17
Research protocol or project proposal [Protocol]	1	21-Feb-17
Validated questionnaire [Questionnaire]	2	16-Feb-17

The R&I Office is keen to support and facilitate research where ever possible. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office. Our contact details are provided on the attached sheet.

Please note that a letter confirming authorisation will not be sent. Please retain a copy of this email in your site file.

We wish you every success with your research.

Should you have any queries or require further information please do not hesitate to contact me.

Kind Regards

Lisa

Lisa Wann
UHL R&I Manager
University Hospitals of
Leicester Leicester General
Hospital Research Office
Gwendolen Road
Leicester
LE5 4PW

Tel: (0116) 258 8239
Work Mobile: 07534989523
Email lisa.wann@uhl-tr.nhs.uk
Fax: (0116) 258 4226

RESEARCH & INNOVATION

Web: www.leicestersresearch.nhs.uk Twitter: @LeicResearch

APPENDIX 14: PARTICIPANT INFORMATION SHEET

United Lincolnshire Hospitals NHS Trust

UNIVERSITY OF LINCOLN

WE ARE MACMILLAN. CANCER SUPPORT

Participant Information Sheet

Self-Management in People Living with and Beyond Cancer in Rural and Urban Settings

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. This should take approximately 5-10 minutes. Talk to others about the study if you wish or ask us if there is anything that is not clear. We ask that you take a little time to decide whether or not you would like to take part.

What is the purpose of the study?

There is limited research exploring whether living in a rural area has a significant bearing on a person's ability to manage their health following cancer treatment. While many factors in the rural setting can promote health (e.g. availability of outdoor recreation, peaceful and quiet environment), there are those that can be detrimental to health. We also lack research using urban comparison groups. This study aims to explore self-management in cancer survivors who live in rural and urban areas across the East Midlands. Self-management in relation to cancer, has been defined as *'awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and well-being.'*

We would like to know about your health promoting behaviours (e.g. exercise, diet, stress management) and how often you practice these. We would also like to explore the knowledge, skills, and confidence people affected by cancer have to self-manage and investigate what enables or prevents people from managing their health.

The findings will increase our understanding of the influence of the rural and urban context of self-management. The research will produce a more solid evidence base for providing tailored and appropriate support to people living with and beyond cancer at a local and national level.

Why have I been invited?

You have been identified through an NHS cancer patient database either at United Lincolnshire Hospitals NHS Trust or University Hospitals of Leicester NHS Trust, and have been invited to participate due to your experience with cancer.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. You are free to withdraw or change your mind at any time without giving a reason. This will have no effect on your care. We would however wish you to note that once data analysis has commenced (expected August 2017) it is not possible to remove individual data as these are anonymised.

What happens if I take part?

If you decide to take part, we would like you to complete the questionnaire provided and send it back to us in the FREEPOST envelope. The questionnaire should take approximately 20 minutes to complete.

If you decide to complete the questionnaire we may wish to access your medical records to gain further information regarding your diagnosis and treatment of cancer. All information accessed will be treated confidentially and anonymised. **By completing and returning the questionnaire, you are giving your consent for the research team to have access to your relevant health information for the purposes of this study.**

Additionally, if you would be happy to attend a research interview, to talk to us in person about your experiences of managing your health since your cancer treatment, we will ask you to initial a box on the enclosed further contact slip indicating your consent to do so. We also ask that you provide your name and contact details. A member of the research team will then make contact with you. Please be assured that these details will be stored securely and separately from your questionnaire response.

Approximately 30 people will be contacted and invited to attend a research interview that will last approximately 60 minutes. Unfortunately, it is unlikely that everyone who registers their interest in being interviewed will be contacted. It is estimated that 7% of all participants will be contacted for the follow- up interview. The interview will take place in a private and convenient location with one researcher. If you would like to do the interview via alternate means such as telephone or skype, please inform the research team when they contact you. We will pay back any reasonable out-of-pocket expenses you incur by taking part, such as travel costs, and we will provide a claim form at the interview.

What are the possible benefits of taking part?

You may benefit as a result of the questionnaire making you carefully consider aspects of your situation that you might not have considered otherwise. You will have the opportunity to express your views on an important topic.

What are the possible risks of taking part?

The study does not involve any treatments or tests, so there is no physical risk involved. Although the interview is not designed to be upsetting at all, sometimes participants may find it distressing to talk about their cancer experience with another person and we will arrange support if that is needed.

What happens when the study ends?

When all the questionnaires have been returned and the interviews been held, a report will be prepared and the findings will be published in academic journals and at relevant conferences. It will be several months before this happens. Once published, a summary of the findings will be made available to all participants and made accessible online, at the University of Lincoln's Mental Health, Health and Social Care Research Group website (http://mhred.lincoln.ac.uk/). Where appropriate the findings may be shared with external partners and used in future research studies. **By completing and returning the questionnaire, you are giving your consent for the information provided to be used in future research studies and shared anonymously with internal and external partners where appropriate.**

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all the information about you, or that you contribute will be anonymised and handled in confidence. Material from interviews will be anonymised fully so that it will not be possible to identify who has taken part or anyone who may be mentioned in the course of discussion.

Should you disclose any kind of information or activity that is deemed illegal, unethical, or indicates that someone is/has been put at risk, the research team would need to pass this on to the appropriate authority.

All recordings and transcriptions will be stored electronically on a password protected computer in a locked office at the University of Lincoln, Brayford Campus. Physical hard copies of questionnaires and discussions will be stored again at the University of Lincoln, in a locked metal filing cabinet which only the immediate research team will have access to. All files will be held for five years after study completion and then destroyed. Paper copies will be shredded and electronic copies deleted.

Who has reviewed the study?

The study has been reviewed externally by an NHS Research Ethics Committee (REC) and internally by the School of Health and Social Care Ethics Committee. Both bodies have given approval for the study.

Who is organising and funding the research?

The research is being carried out by a team (David Nelson, Dr Ros Kane, Dr Christine Jackson and Dr Ian Mcgonagle) from the School of Health and Social Care at the University of Lincoln. It is funded by UK charity, Macmillan Cancer Support.

About Macmillan Cancer Support

From help with money worries and advice about work, to someone who'll listen if you just want to talk, we'll be there. We'll help you make the choices you need to take back control, so you can start to feel like yourself again.

No one should face cancer alone. For support, information or if you just want to chat, call Macmillan free on 0808 808 00 00 (Monday to Friday, 9am–8pm) or visit macmillan.org.uk

How can I find out more?

If you would like more information about the study before you make up your mind, you can contact the Chief Investigator, David Nelson by telephone (01522 83 7343), e-mail (dnelson@lincoln.ac.uk) or post (University of Lincoln, School of Health and Social Care, Brayford Pool, Lincoln, LN6 7TS).

What if there is a problem?

If you have a concern or a complaint about any aspect of this study, you should contact the Chair of the School of Health and Social Care Ethics Committee, Professor Mo Ray by e-mail (mray@lincoln.ac.uk) or post (University of Lincoln, School of Health and Social Care, Brayford Pool, Lincoln, LN6 7TS).

Where can I get independent advice about taking part in the study?

If you would like to get some independent advice about your rights as a research participant, you can contact the local R&D office below:

Lincolnshire: Department of Research and Development, United Lincolnshire Hospitals NHS Trust, Lincoln County Hospital, Greetwell Road, Lincoln, LN2 5QY. Tel: 01522 573941 Email: RandD@ULH.nhs.uk

Leicestershire: Research Office, University Hospitals of Leicester NHS Trust, Leicester General Hospital, Gwendolen Road, Leicester, LE5 4PW. Tel: 0116 258 8351 Email: RIAdmin@uhl-tr.nhs.uk

Where can I find out about other cancer support and services?

If you have a query regarding further cancer support you can contact the Macmillan Cancer Support Information and Support Service below:

Lincolnshire: Macmillan Cancer Information and Support, Lincoln County Hospital, Greetwell Road, LN2 5QY. Tel: 01522 573799 Email: macmillan.infosupport@ulh.nhs.uk

Leicestershire: Cancer Information Centre, Osbourne Building, Leicester Royal Infirmary, Leicester, LE1 5WW. Tel: 0116 258 6189 Email: cancerinfo@uhl-tr.nhs.uk

We would like to thank you for taking the time to read this sheet and considering taking part in the research study.

APPENDIX 15: NHS TRUST COVER LETTER FROM CLINICAL NURSE SPECIALIST (CNS)

Trust Headquarters
University Hospitals of Leicester Headquarters
Level 3, Balmoral
Building Leicester
Royal Infirmary
Infirmary Square
Leice
ster
Leicesters
hire LE1
5WW

PALS (Patient Advice and Liaison Service) Tel: 08081 788337
Email: pils.complaints.compliments@uhl-tr.nhs.uk

Dear Sir or Madam

RE: Self-Management in People Living with and Beyond Cancer in Rural and Urban Settings

University Hospitals of Leicester NHS Trust are supporting a research study that is being carried out by a team of researchers from the University of Lincoln. The study is being funded by Macmillan Cancer Support. We are contacting you on behalf of the research team, as we do not pass your personal details on without your consent.

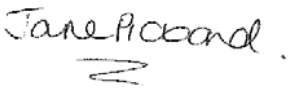
The study is interested in how people living with and beyond cancer who live in rural and urban areas manage their health and healthcare following treatment. The research team would very much like to hear your views on the subject of self-management and would be grateful if you would complete the enclosed questionnaire, and return in the FREEPOST envelope provided.

As well as the questionnaire, the researchers would also like to speak to some people about what helps or prevents them from managing their health. Enclosed with this letter you will find an information sheet alongside a further contact slip which includes a tick box section indicating your acceptance to take part in a one-to-one discussion, even if you do not wish to take part in a discussion the researchers would still very much appreciate it if you would complete and return the questionnaire in the FREEPOST envelope. The findings will eventually be used to help support people living with and beyond cancer at a local and national level.

As is usual with research studies, participation is entirely voluntary. Should you decide to take part, your response will be treated confidentially and presented anonymously. Your care will not be affected in any way.

If you have any queries, please do not hesitate to get in touch with us or the research team directly (contact details found on the information sheet). Finally, if you would like some independent advice on taking part in a research study, you can contact the local NHS Research & Development office, details also found on the information sheet. Thank you for your time.

Yours faithfully,



Jane Pickard
Macmillan Lead Cancer Nurse
University Hospitals of Leicester NHS Trust

Every effort has been made to ensure that this questionnaire has been sent to the appropriate patient population through checking of patient databases. If you have recently experienced a recurrence of cancer or are unwell for any other reason and feel you would be unable to take part in this research, please accept our apologies for sending this letter to you. For general support you can contact Macmillan Cancer Support on Freephone 0808 808 00 00 or via their website macmillan.org.uk.

APPENDIX 16: CONSENT FORM

University Hospitals of Leicester NHS Trust | UNIVERSITY OF LINCOLN | United Lincolnshire Hospitals NHS Trust

CONSENT FORM

Self-Management in People Living with and Beyond Cancer in Rural and Urban Settings

Name of Researcher: David Nelson (dnelson@lincoln.ac.uk; 01522 837343)

Please initial box

1. I confirm that I have read and understand the information sheet dated 20/03/17 (Version 2.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw up to the point of data analysis (expected December 2017) without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that all the information I give will be STRICTLY CONFIDENTIAL and that results from this study will only be presented in anonymous form. ☐
4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the research team at the University of Lincoln or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
5. I understand that should I disclose any kind of information or activity that is deemed illegal, unethical, or indicates that someone is/has been put at risk, the research team will need to inform the appropriate authority. ☐
6. I understand that the information I provide will be reported on in a range of outputs (e.g. PhD thesis, research reports, conference presentations, journal articles). ☐
7. I understand that the data from this research may be shared anonymously with internal and external partners, and utilised in future studies where appropriate. ☐
8. I agree to the interview being digitally recorded and transcribed. ☐
9. I understand that I will undertake one interview lasting approximately 60 minutes with one researcher. ☐
10. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person Taking Consent	Date	Signature

Consent Form: Version 2.0. Date: 16/02/17
When completed: 1 for participant; 1 for researcher site file

APPENDIX 17: CONFIDENTIALITY AGREEMENT FOR EXTERNAL TRANSCRIPTION

CONFIDENTIALITY AGREEMENT

BETWEEN

UNIVERSITY OF LINCOLN

AND

NEAL MARTIN

RELATING TO

Transcribing Services

THIS AGREEMENT is made on 16 / 05 / 2019

BETWEEN:-

(1) **UNIVERSITY OF LINCOLN** of Brayford Pool, Lincoln, LN6 7TS (the **"University**"); and

(2) **NEAL MARTIN** of 3 Paddock Close, Market Rasen, LN8 3DG (the **"Transcriber**").

Each a "Party" and together the "Parties".

BACKGROUND

(A) The University wishes the Transcriber to undertake transcriptions for various University projects.

(B) As part of these discussions/activities, Confidential Information (as defined below) will be disclosed by a party to the other party.

(C) The Disclosing Party (as defined below) requires that Confidential Information revealed to the Receiving Party (as defined below) remains confidential and is not used by the Receiving Party for any purpose other than the Permitted Purpose.

IT IS AGREED as follows:-

1. **INTERPRETATION**

1.1 In this Agreement:-

"Confidential Information"	means all information in whatever form (including, without limitation, in written, oral, visual or electronic form, or on tape or disk) relating to the Permitted Purpose that is directly or indirectly disclosed ,whether before or after the date of this Agreement, to a party or any of its representatives ("**Receiving Party**") by any agent or employee of the other party ("**Disclosing Party**"), or which comes to the Receiving Party's attention in connection with the Permitted Purpose but excludes the information in Clause 2.2 below.
"Copies"	copies of Confidential Information including any document, electronic file, note, extract, analysis, study, plan, compilation or any other way of representing or recording and recalling information which contains, reflects or is derived or generated from Confidential Information
"Data Protection Legislation"	means any data protection legislation from time to time in force in the UK including the Data Protection Act 2018 or any successor legislation plus (for so long as and to the extent that the law of the European Union has legal effect in the UK) the General Data Protection Regulation ((EU) 2016/679) and any other directly applicable European Union regulation relating to privacy.
"**Permitted Purpose**"	Means discussions regarding the undertaking of undertake transcriptions for various University projects

1.2 Clause and schedule headings do not affect the interpretation of this Agreement.

- A person includes a corporate or unincorporated body.
- A reference to a law is a reference to it as it is in force for the time being, taking account of any amendment, extension, application or re-enactment and includes any subordinate legislation for the time being in force made under it.
- Writing or written includes faxes and e-mail.
- Words in the singular include the plural and in the plural include the singular.

(D) **RECEIVING PARTY'S OBLIGATIONS**

- In consideration for the Disclosing Party making Confidential Information available to the Receiving Party, the Receiving Party shall:

- keep the Confidential Information secret;
- use the Confidential Information only for the Permitted Purpose;
- not directly or indirectly disclose the Confidential Information (or allow it to be disclosed), in whole or in part, to any person or make Copies unless permitted by this Agreement;
- use its reasonable endeavours to ensure that no person is able to access Confidential Information from the Receiving Party, its officers, employees or agents unless authorised by the Disclosing Party to do so; and
- inform the Disclosing Party immediately on becoming aware, or suspecting, that an unauthorised person has become aware of Confidential Information.

- Information is not Confidential Information for the purposes of this Agreement if:
  - the information is, or subsequently becomes, public knowledge other than as a direct or indirect result of the information being disclosed in breach of this Agreement; or
  - the Receiving Party can establish, to the reasonable satisfaction of the Disclosing Party, that it found out the information from a source not connected with the Disclosing Party and that such source is not under any obligation of confidence in respect of that information; or
  - the Receiving Party can establish, to the reasonable satisfaction of the Disclosing Party, that the information was known to the Receiving Party before the date of this Agreement and that it was not under any obligation of confidence in respect of that information;
  - the Receiving Party can establish, to the reasonable satisfaction of the Disclosing Party, that the information was developed independently by the Receiving Party without reference to the Confidential Information of the Disclosing Party; or
  - the parties agree in writing that it is not confidential.
- The Receiving Party may disclose Confidential Information only;
  - to such officers and employees of the Receiving Party as are required to receive the Confidential Information for the Permitted Purpose;

  - to professional advisers or consultants engaged to advise the Receiving Party in connection with the Permitted Purpose;
  - to people whom the Disclosing Party agrees in writing may receive the information; and
  - to the extent permitted by Clause 4.
- The Receiving Party shall:
  - inform any person to whom it discloses the Confidential Information that the information is confidential; and

- procure that any person to whom it discloses the Confidential Information (other than disclosures under Clause 4) complies with this Agreement as if they were the Receiving Party and, if the Disclosing Party so requests, procure that they enter into a confidentiality agreement with the Disclosing Party on terms equivalent to those contained in this Agreement.

- The Receiving Party may make only such Copies as are strictly necessary for the Permitted Purpose and shall:

  - clearly mark all Copies as confidential;

  - ensure that all Copies supplied to it or made by it can be separately identified from its own information; and

  - use its reasonable endeavours to ensure that all Copies within its control are protected against theft or unauthorised access and that no person discovers Confidential Information from the Receiving Party unless authorised.

- The Receiving Party shall, immediately on the Disclosing Party's written request, supply the Disclosing Party with a list showing, to the extent reasonably practical:

  - where all Copies supplied to the Receiving Party by the Disclosing Party are held;

  - all Copies that have been made by the Receiving Party or the persons to whom it has disclosed the Confidential Information (except where the Copies contain insignificant extracts from or references to Confidential Information) and where they are held; and

  - the names and addresses of every person to whom Confidential Information has been disclosed and a copy of the confidentiality agreements signed by them in compliance with Clause 2.4.2.

- If discussions in relation to the Permitted Purpose cease, or the Disclosing Party so requests in writing at any time, the Receiving Party shall immediately:

  - return to the Disclosing Party all the Confidential Information received by the Receiving Party; and

  - destroy or permanently erase all Copies supplied to it or made by it, or by the persons who have received Confidential Information, [other than Copies that contain insignificant extracts from, or references to, Confidential Information, or that contain no Confidential Information other than information disclosed under Clause 4.

- Nothing in Clause 2.7 shall require the Receiving Party to return or destroy Confidential Information or Copies that the Receiving Party, or the persons to whom the Confidential Information or Copies have been disclosed, are required to retain by applicable law or to satisfy the rules or regulations of a regulatory body or stock exchange to which such person is subject.

- The Receiving Party shall, immediately on the request of the Disclosing Party, confirm in writing that it has complied with its obligations under Clause 2.7.

(E) **AUTHORISED CONTACT**

- All communications with the each party about the Permitted Purpose shall be addressed

- Ros Kane (or any other project lead) for the University.

- Neal Martin, the Transcriber.

2. **FORCED DISCLOSURE**

2.1 Subject to Clause 4.2, the Receiving Party may disclose Confidential Information to the minimum extent required by:

- any order of any court of competent jurisdiction or any competent judicial, governmental or regulatory body; or

- the laws or regulations of any country with jurisdiction over the affairs of the Receiving Party (provided that in the case of any disclosure under the Freedom of Information Act 2000, none of the exemptions to that Act applies to the information disclosed).

2.2 Before the Receiving Party discloses any information under this Clause 4, the Receiving Party shall (to the extent permitted by law) use its reasonable endeavours to:

- inform the Disclosing Party of the full circumstances of the disclosure and the information that will be disclosed, and take all such steps as may be reasonable and practicable in the circumstances to agree the contents of such disclosure with the Disclosing Party before making the disclosure;

- consult with the Disclosing Party as to possible steps to avoid or limit disclosure and take those steps where they would not result in significant adverse consequences to the Receiving Party;

- gain assurances as to confidentiality from the body to whom the information is to be disclosed; and

- where the disclosure is by way of public announcement, agree the wording with the Disclosing Party in advance.

2.3 The Receiving Party shall co-operate with the Disclosing Party if the Disclosing Party decides to bring any legal or other proceedings to challenge the validity of the requirement to disclose Confidential Information (at the Disclosing Party's cost and expense).

2.4 If the Receiving Party is unable to inform the Disclosing Party before Confidential Information is disclosed, the Receiving Party shall (to the extent permitted by law) inform the Disclosing Party immediately after the disclosure of the full circumstances of the disclosure and the information that has been disclosed.

(1) **TIME**

This Agreement shall continue for a period of 36 months from the date of this Agreement.

The obligations contained in this Agreement shall until such time as the Confidential Information ceases to be confidential and is in the public domain.

(2) **INDEMNITY**

The Receiving Party shall (in addition to, and without affecting, any other rights or remedies the Disclosing Party may have whether under statute, common law or otherwise) indemnify, and keep indemnified, the Disclosing Party and its officers, employees, advisers or agents (each an "**Indemnified Person**") from and against all actions, claims, demands, liabilities, damages, losses, costs, charges and expenses (including, without limitation, consequential losses, loss of profit and loss of reputation and all interest, penalties and legal and other professional costs and expenses) that an Indemnified Person may suffer or incur in connection with, or arising (directly or indirectly) from, any breach or non-performance by the Receiving Party, or any person to whom it has disclosed or given access to any part of the Confidential Information or any Copies, of any of the provisions of this Agreement.

(3) **WHOLE AGREEMENT AND CONDUCT OF NEGOTIATIONS**

- This Agreement is the whole agreement between the parties and supersedes any arrangements, understanding or previous agreement between them relating to the subject matter covered by this Agreement.

- The Confidential Information may not be accurate or complete and the Disclosing Party makes no representation or warranty as to the accuracy, completeness or reasonableness of the Confidential Information and no such representation or warranty shall be implied. The Disclosing Party is not liable to the Receiving Party or to any person to whom the Receiving Party discloses the Confidential Information if it is relied on.

- Nothing in this Clause 7 operates to limit or exclude any liability for fraud.

(4) **COSTS**

Unless otherwise specified, all costs in connection with the negotiation, preparation, execution and performance of this Agreement (and any documents referred to in it) and the consideration or evaluation of the Confidential Information shall be borne by the party that incurred the costs.

(5) **ASSIGNMENT**

The Receiving Party may not assign any of its rights under this Agreement or any document referred to in it without the prior written consent of the Disclosing Party.

(6) **THIRD PARTY RIGHTS AND INTELLECTUAL PROPERTY**

- Except as provided in this Clause 10, this Agreement is made for the benefit of the parties to it and their successors and permitted assigns and is not intended to benefit, or be enforceable by, anyone else.

- The parties may terminate, rescind or vary this agreement without the consent of any person who is not a party to this Agreement.

- All Confidential Information is the property of the relevant Disclosing Party. The disclosure to the Receiving Party of any Confidential Information shall not give the Receiving Party any

licence or other rights whatsoever in respect of any part of such Confidential Information beyond the rights contained in this Agreement.

(3) **SEVERANCE**

- If any court or administrative body of competent jurisdiction finds any provision of this agreement to be invalid, unenforceable or illegal, the other provisions of this agreement shall remain in force.

- If any invalid, unenforceable or illegal provision would be valid, enforceable or legal if some part of it were deleted, the provision shall apply with whatever modification is necessary to make it valid, enforceable and legal.

(F) **VARIATION AND WAIVER**

- A variation of this Agreement shall be in writing and signed by or on behalf of all parties.

- A waiver of any right under this Agreement is only effective if it is in writing and it applies only to the person to whom the waiver is addressed and the circumstances for which it is given.

- A person that waives a right in relation to one person, or who takes or fails to take any action against that person, does not affect its rights against any other person.

- No failure to exercise or delay in exercising any right or remedy provided under this Agreement or by law constitutes a waiver of such right or remedy or will prevent any future exercise in whole or in part thereof.

- No single or partial exercise of any right or remedy under this Agreement shall preclude or restrict the further exercise of any such right or remedy.

- Rights arising under this Agreement are cumulative and do not exclude rights provided by law.

(G) **GOVERNING LAW AND JURISDICTION**

- This Agreement and any disputes or claims arising out of, or in connection with, its subject matter are governed by and construed in accordance with the laws of England.

- The parties irrevocably agree that the courts of England have exclusive jurisdiction to settle any dispute or claim that arises out of or in connection with this Agreement.

- This Agreement may be executed in any number of counterparts, each of which when executed (and delivered) will constitute an original of this Agreement, but all counterparts will together constitute the same agreement. No counterpart will be effective until each party has executed at least one counterpart.

14. **DATA PROTECTION**

14.1 All expressions used in this Clause 14.1 beginning with a capital letter (and not defined elsewhere in this Agreement) have the meaning given to them in the Data Protection Legislation. No Personal Data will be shared as part of the arrangements contemplated by this Agreement as no living individual will be capable of being identified from the information shared between the Parties. If, at a later date, it is necessary to share Personal Data as part of the arrangements contemplated by this Agreement then the Parties shall enter into a separate Data Sharing Agreement or Data Processing Agreement (as appropriate).

This Agreement has been entered into on the date stated at the beginning of it.

Name: Andrew Stevenson
Title: Director – Research & Enterprise
Date: 16/05/2019
SIGNED
For and on behalf of
THE UNIVERSITY OF LINCOLN

.....

Name: Neal Martin

Title: Transcriber

Date: 20/05/2019

SIGNED
For and on behalf of
NEAL MARTIN

.....

APPENDIX 18: LETTER OF SUPPORT FROM A STATISTICIAN

West of Scotland REC 4
West Ambulatory Care Hospital
Dalnair Street
Yorkhill
Glasgow
G3 8SJ

3rd April 2017

To whom it may concern:

RE: Letter from Statistician (IRAS Project ID: 204679; REC Ref: 17/WS/0054)

This letter is to confirm that I have read the protocol prepared for this study, and that in my opinion the statistical methods and techniques mentioned are appropriate for the research that is planned.

In addition to this I have worked with the Chief Investigator to decide upon the sample size (n=417). A sample size calculation was performed based on expected variations in the Health-Promoting Lifestyle Profile ii. The calculation allowed for a 20% difference between scores, assumed a statistical significance level of 0.5, and a test with 95% power, giving a required sample of 417.

Please contact me if you require any further information.

Best wishes,

Dr Paul Turner
Senior Lecturer
School of Health and Social Care
University of Lincoln
Lincoln
LN6 7TS

Email: pturner@lincoln.ac.uk
Tel: 01522 88 6379

APPENDIX 19: FURTHER CONTACT SLIP

FURTHER CONTACT

Self-management in People Living with and Beyond Cancer in Rural and Urban Settings

We would like to invite some participants to discuss their experiences in further detail. Would you be happy to be contacted by one of our researchers to discuss your experiences of managing your health and what helps or prevents you from doing so? (Please initial the box)

☐ I am happy to be contacted about the possibility of taking part in a research interview with a member of the research team.

If you are happy for us to contact you please provide your contact details below and return in the FREEPOST envelope with your questionnaire. **Please note that any contact details you supply will be kept separate from the completed questionnaire and will not be used to identify you with the answers that you have provided.**

Name:……

Telephone number:……...

Email address (if applicable):…….

APPENDIX 20: RECRUITMENT LETTER TO NHS TRUST

UNIVERSITY OF LINCOLN

24 May 2017

Dear Charlie and Sarah,

RE: Research pack mail out

- Please find enclosed 417 envelopes (cover letter; information sheet; return envelope) in box 1 and 417 questionnaires in box 2. Please can you confirm receipt to me via email and again confirm that these have been mailed out via email.

- Please input a unique ID code into the box on page 2 of the questionnaire and keep a record of this along with medical data in relation to the patient's cancer type, treatment received, time since diagnosis, time since treatment began. The questionnaire makes it clear that by completing and returning it that the participant gives consent for us to have access to this information. Once the ID code has been put on the questionnaire, please put this in the back of the envelope, seal and put the participant's address on the front.

- Once recruitment has completed, please invoice the University of Lincoln for postage costs and reimbursement of staff time.

- Please send to patients on your database that meet the following criteria:

Inclusion Criteria	**Exclusion Criteria**
Aged 18 and over	Under 18
Confirmed primary diagnosis of cancer	Secondary diagnosis of cancer
Undergone primary cancer treatment within the last 5 years	Evidence of metastatic spread/local recurrence of disease
	Started active oncology treatment within last 12 months
	Treatment start date more than five years ago
	Treated for best supportive care

Any issues with the above please do not hesitate to get in touch. Let me take this opportunity to thank you both for all of your help and support.

Yours sincerely,

David Nelson
Macmillan Research Fellow
University of Lincoln

School of Health and Social Care

University of Lincoln Brayford Pool Lincoln LN6 7TS United Kingdom
www.lincoln.ac.uk 01522 83 7343 dnelson@lincoln.ac.uk

APPENDIX 21: SPSS OUTPUT FOR T-TESTS AND LEVENE'S TEST

Group Statistics

	Rural or Urban	N	Mean	Std. Deviation	Std. Error Mean
Mean of Health Promoting Lifestyle Profile	Rural	72	2.6952	.44394	.05232
	Urban	87	2.4136	.41617	.04462
PAM Activation Score (0-100) (Need to answer 10 of 13 questions for valid score)	Rural	97	63.3062	13.66358	1.38733
	Urban	114	59.5895	12.75306	1.19443
Cancer Survivors Self-efficacy Scale 11 item Mean	Rural	98	7.8562	1.70495	.17223
	Urban	106	7.0926	1.96458	.19082

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Mean of Health Promoting Lifestyle Profile	Equal variances assumed	.114	.736	4.122	157	.000	.28167	.06834	.14669	.41666
	Equal variances not assumed			4.096	147.442	.000	.28167	.06876	.14579	.41756
PAM Activation Score (0-100) (Need to answer 10 of 13 questions for valid score)	Equal variances assumed	.814	.368	2.042	209	.042	3.71671	1.82049	.12783	7.30559
	Equal variances not assumed			2.030	198.438	.044	3.71671	1.83067	.10665	7.32677
Cancer Survivors Self-efficacy Scale 11 item Mean	Equal variances assumed	1.013	.315	2.954	202	.004	.76359	.25848	.25393	1.27325
	Equal variances not assumed			2.971	201.212	.003	.76359	.25705	.25674	1.27044

Group Statistics

	Rural or Urban	N	Mean	Std. Deviation	Std. Error Mean
Health Responsibility Subscale	Rural	95	2.2713	.50884	.05221
	Urban	108	2.0422	.49730	.04785
Physical Activity Subscale	Rural	92	2.2065	.71302	.07434
	Urban	116	1.9817	.71461	.06635
Nutrition Subscale	Rural	100	2.8844	.53273	.05327
	Urban	113	2.5860	.59674	.05614
Spiritual Growth Subscale	Rural	90	2.8568	.60130	.06338
	Urban	111	2.5996	.63675	.06044
Interpersonal Relations Subscale	Rural	94	3.0969	.57105	.05890
	Urban	110	2.7970	.54907	.05235
Stress Management Subscale	Rural	96	2.5143	.54588	.05571
	Urban	112	2.4587	.53545	.05060

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Health Responsibility Subscale	Equal variances assumed	.557	.456	3.241	201	.001	.22916	.07072	.08973	.36860
	Equal variances not assumed			3.236	196.470	.001	.22916	.07082	.08950	.36883
Physical Activity Subscale	Equal variances assumed	.014	.907	2.256	206	.025	.22484	.09967	.02834	.42134
	Equal variances not assumed			2.257	195.542	.025	.22484	.09964	.02833	.42135
Nutrition Subscale	Equal variances assumed	.546	.461	3.829	211	.000	.29841	.07793	.14479	.45203
	Equal variances not assumed			3.856	210.982	.000	.29841	.07739	.14585	.45097
Spiritual Growth Subscale	Equal variances assumed	.739	.391	2.919	199	.004	.25719	.08811	.08345	.43093
	Equal variances not assumed			2.937	194.394	.004	.25719	.08758	.08446	.42992
Interpersonal Relations Subscale	Equal variances assumed	.120	.729	3.818	202	.000	.29996	.07856	.14506	.45486
	Equal variances not assumed			3.806	194.444	.000	.29996	.07880	.14454	.45537
Stress Management Subscale	Equal variances assumed	.115	.735	.740	206	.460	.05562	.07515	-.09254	.20377
	Equal variances not assumed			.739	199.929	.461	.05562	.07526	-.09279	.20402

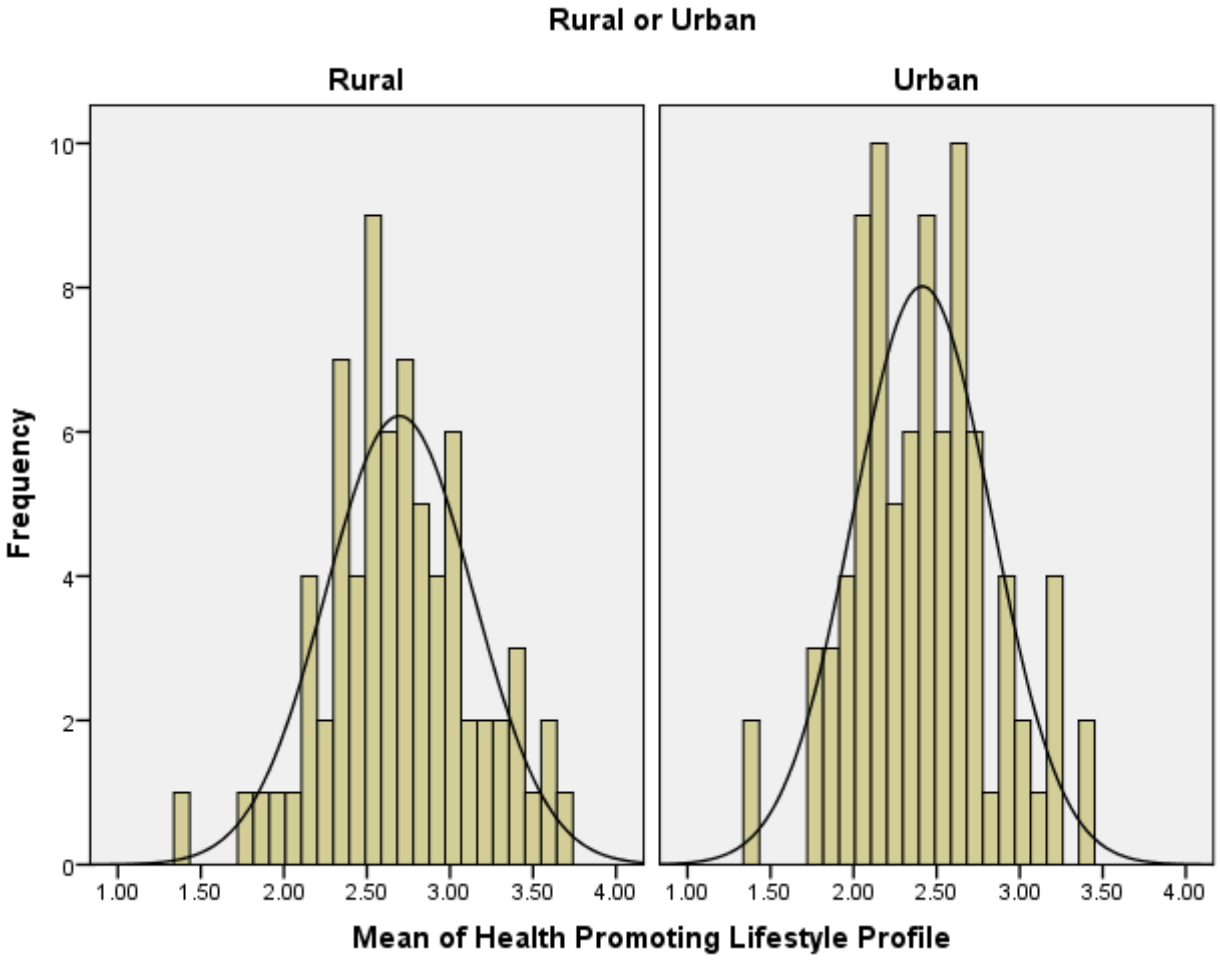
Group Statistics

	Rural or Urban	N	Mean	Std. Deviation	Std. Error Mean
How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	Rural	99	7.2525	2.39192	.24040
	Urban	112	6.4643	2.61296	.24690
How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	Rural	99	7.8485	2.14459	.21554
	Urban	112	6.8750	2.54730	.24070
How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	Rural	101	7.9901	2.18858	.21777
	Urban	115	6.7391	2.57207	.23985
How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	Rural	102	7.3235	2.41760	.23938
	Urban	115	6.5826	2.49203	.23238
How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	Rural	102	7.9412	1.98920	.19696
	Urban	115	7.5217	2.10408	.19621
How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	Rural	102	7.8725	2.17853	.21571
	Urban	113	7.3982	2.24619	.21130
How confident are you that you can access information about your cancer and any effects of the diagnosis and treatment?	Rural	102	8.2941	2.07574	.20553
	Urban	117	7.8376	2.20093	.20348
How confident are you that you can access people to help and support you when you have problems caused by cancer and/or cancer treatment?	Rural	103	8.2039	2.30668	.22728
	Urban	117	7.6154	2.36295	.21846
How confident are you that you can deal with the problems cancer and/or cancer treatment has caused by yourself?	Rural	102	7.5980	2.30049	.22778
	Urban	116	6.6897	2.60906	.24225
How confident are you to contact your doctor about problems caused by your cancer/treatment?	Rural	102	8.4314	2.18233	.21608
	Urban	118	7.5000	2.66587	.24541
How confident are you that you can get support with problems caused by your cancer/treatment from health and/or social care professionals?	Rural	101	7.9505	2.35956	.23479
	Urban	117	7.3077	2.53752	.23459

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	Equal variances assumed	1.125	.290	2.275	209	.024	.78824	.34649	.10518	1.47130
	Equal variances not assumed			2.287	208.736	.023	.78824	.34460	.10889	1.46759
How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	Equal variances assumed	4.394	.037	2.981	209	.003	.97348	.32652	.32978	1.61719
	Equal variances not assumed			3.013	208.523	.003	.97348	.32310	.33653	1.61044
How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	Equal variances assumed	3.971	.048	3.821	214	.000	1.25097	.32736	.60571	1.89622
	Equal variances not assumed			3.861	213.796	.000	1.25097	.32396	.61240	1.88954
How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	Equal variances assumed	.529	.468	2.217	215	.028	.74092	.33423	.08213	1.39971
	Equal variances not assumed			2.221	213.262	.027	.74092	.33362	.08330	1.39854
How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	Equal variances assumed	.707	.401	1.504	215	.134	.41944	.27895	-.13039	.96927
	Equal variances not assumed			1.509	214.112	.133	.41944	.27801	-.12855	.96743
How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	Equal variances assumed	.471	.493	1.568	213	.118	.47432	.30243	-.12182	1.07046
	Equal variances not assumed			1.571	211.891	.118	.47432	.30196	-.12091	1.06954
How confident are you that you can access information about your cancer and any effects of the diagnosis and treatment?	Equal variances assumed	.678	.411	1.572	217	.117	.45651	.29038	-.11582	1.02884
	Equal variances not assumed			1.578	215.642	.116	.45651	.28921	-.11354	1.02656
How confident are you that you can access people to help and support you when you have problems caused by cancer and/or cancer treatment?	Equal variances assumed	.437	.509	1.864	218	.064	.58850	.31573	-.03378	1.21078
	Equal variances not assumed			1.867	215.666	.063	.58850	.31525	-.03286	1.20986
How confident are you that you can deal with the problems cancer and/or cancer treatment has caused by yourself?	Equal variances assumed	2.571	.110	2.710	216	.007	.90838	.33521	.24767	1.56909
	Equal variances not assumed			2.732	215.998	.007	.90838	.33252	.25299	1.56378
How confident are you to contact your doctor about problems caused by your cancer/treatment?	Equal variances assumed	6.582	.011	2.808	218	.005	.93137	.33174	.27755	1.58520
	Equal variances not assumed			2.848	217.381	.005	.93137	.32699	.28691	1.57584
How confident are you that you can get support with problems caused by your cancer/treatment from health and/or social care professionals?	Equal variances assumed	1.160	.283	1.926	216	.055	.64280	.33368	-.01489	1.30049
	Equal variances not assumed			1.937	214.789	.054	.64280	.33190	-.01140	1.29700

APPENDIX 22: HISTOGRAM AND NORMALITY TESTS HPLP-II



Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Rural or Urban	Statistic	df	Sig.	Statistic	df	Sig.
Mean of Health Promoting Lifestyle Profile	Rural	.062	72	.200*	.989	72	.778
	Urban	.072	87	.200*	.986	87	.445

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

The p value is >0.05, therefore, we can reject the null hypothesis and conclude that the data comes from a normal distribution.

APPENDIX 23: UNIVERISTY OF LINCOLN LONE WORKING POLICY

UNIVERSITY OF LINCOLN

Lone Working Policy

The University of Lincoln's policy is to avoid the need to work alone where possible. Where this is not possible, a risk assessment will be carried out to identify and implement measures necessary to minimise any risk.

Legal Requirements

There is no overall legal prohibition on working alone, but the general duties of the Health and Safety at Work etc Act and the specific duties of the Management of Health and Safety at Work Regulations still apply. These require the identification of any hazards, assessment of any risks involved, and devising and implementing safe working arrangements to ensure that the risks are either eliminated or adequately controlled.

Responsibilities of Senior Managers, Heads of Department and Heads of College

- To ensure that all their staff are aware that a Risk Assessment must to be carried out and a Lone Working Approval form signed before lone working takes place.
- To identify circumstances where staff members may be expected to operate as a lone worker, and in the case of Colleges where students may be expected to operate in their studies as a lone worker.
- To ensure that Risk Assessments are carried out in their area of responsibility and to identify members of their team to undertake these risk assessments and ensure they have received suitable and sufficient training.
- Ensure that the safe working arrangements identified by the risk assessment are put into place to control or minimise the risks of lone working for all of their employees, students, visitors and contractors
- To ensure that the least hazardous procedures are used in all their operations to limit the exposure to risk of the lone worker. The extent of any supervision required is a management decision; it should not be left to individuals to decide that they require assistance.
- Grant, prohibit or rescind permission to those planning to engage in lone working activities
- Ensure that information about relevant hazards and related emergency procedures is given to all employees, students, visitors and contractors undertaking lone working

V 1.1
Reviewed April 2014
Reviewed April 2018

- Review the arrangements periodically
- Take appropriate action when non-compliance is brought to their attention
- Check that any reported accidents, hazards or near misses by those working alone are properly investigated, monitored and appropriate action taken, particularly to remedy any identified trends.

Responsibilities of line managers

Line managers, including principal investigators, laboratory managers, maintenance team leaders etc. are responsible for:

- Implementing localised control measures to avoid 'lone working' situations within buildings and geographical locations where students and staff frequently work unsupervised, e.g. the library
- Completing person specific 'Lone Working' risk assessments or liaising with persons nominated to undertake the risk assessment.

  NB A person specific risk assessment needs to consider the individual(s) involved as some may be at greater risk than others, for example new mothers and pregnant women.
- Ensure all team members required to undertake lone working are involved in the risk assessment process.
- Ensuring that any areas where members of their team may occasionally work alone are considered within activity based risk assessments. This may highlight a requirement to undertake specific lone working risk assessments when required.
- Communicate any findings from the risk assessment process to the member of staff undertaking lone working activities and clarify or review if the member of staff has any concerns.
- Ensuring that the least hazardous procedures are used
- Ensuring that any identified control measures are implemented, validated and monitored
- Ensuring a Lone Working Approval Form (Appendix Two) is completed and signed by Head of Department or Head of College.
- Forwarding a copy of the Lone Working Approval Form (Appendix Two) to the Estates Services Manager or respective Campus Manager (along with an attached copy of the risk assessment) when lone working is to be undertaken out of normal working hours (normal working hours are defined as 08:00 – 18:00).

- Ensuring that people under their control are competent to carry out designated tasks. Where an individual does not have the necessary competence, ensuring they are suitably supervised or prohibited from areas or tasks beyond their capabilities

- Ensuring employees or visitors under their control are provided with suitable and sufficient information, training, instruction and supervision

- Ensure records of any training and refresher training, for employees or visitors under their control, are maintained and retained.

- Ensuring that other local arrangements, including adequate measures to deal with fire, first aid, spillages, power failures and other emergencies, are in place, especially for secure areas

- Taking appropriate action when non-compliance is brought to their attention

- To ensure that employees report and record any incidents, threats, intimidation or other potential hazards and those details of any reported incidents are then passed to Senior Managers through the University's reporting system.

- Provide suitable advice and support to the employee following such an incident, including offering the University's counselling service if appropriate.

- If lone working is a regular occurrence, monitoring the individual by:
    - Visiting during the work,
    - Reviewing the work,
    - Ensuring the scope of the agreed work is not exceeded and
    - Checking that the risk assessment remains valid

Responsibilities of person undertaking the Risk Assessment

- To undertake a suitable and sufficient risk assessment following the procedures detailed in this guidance and appendices
- Communicate the results of the assessment to Head of Department/ Dean of Faculty and all staff involved with, or potentially affected by the lone working e.g. the person working alone and anyone with a role to play in ensuring their safety.
- Keep a written record of the Risk assessment available for information and audit purposes

Responsibilities of staff

All members of staff are:

- To be aware of the requirements of this policy. Particularly the requirement for lone working activities to be risk assessed and authorised before taking place.

- To notify their Line Manager of the existence/intention/need for lone working so that a Risk Assessment can be carried out and to raise any specific or personal concerns relating to lone working with their line manager.

- To work with the person carrying out the Risk Assessment to ensure that all aspects of the lone working are considered.

- To follow any control measures identified by the Risk assessment

- If an employee finds themselves in a situation that could be considered as lone working, they must ensure their line manager is aware of the circumstances at the earliest opportunity.

- Take reasonable care while at work for their own health and safety and for that of people who may be affected by their acts or omissions

- Not to misuse safety equipment or Safe Systems of Work provided by the University.

- Ensure that they are familiar with the University's and their department's procedures to deal with fire, first aid, spillages, power failures and other emergencies

- Follow the agreed procedures for emergency contact, such as:
    - Providing a contact number to their line manager
    - Informing their line manager or a work colleague of the time that he or she expects to leave the premises
    - Filling out the building entry log book on starting work outside normal hours and upon leaving the building, where such a log book is present in a building, or reporting to Security Control on starting and leaving if a log book is not present in the building

- Inform their line manager immediately if there are any problems or changes to arrangements

- Keep within the scope of the agreed work and work areas.

- To report all incidents and hazards to their Line manager and through the University's reporting system

APPENDIX 24: EXAMPLE OF COMPLETED INTERVIEW TRANSCRIPT

QUAL06

Qualitative Interviews: Self-Management in PLWABC in Rural and Urban Settings.

Face-to-Face Interview; Participant's Home; 15/11/17, 14:30

Audio File: QUAL06_151117_ID0119.Wav

Interviewer: David Nelson, University of Lincoln.

Participant Information: QUAL06, ID0119, Female, 39, Gynaecological Cancer, Resident in a Rural Area (E1: Rural Village) in Nottinghamshire.

DN: So if we can just start with a personal introduction, anything you would like to say about yourself?

Eh…I am, how old am I? I'm 39 years old, I'm a florist, I have quite an active lifestyle, I like being outside, I have lots of animals, I have no children, that's me I guess.

DN: So you were telling me at the beginning, how long have you been living here?

So, I've lived here for six years, I've been up in the area for six years. I used to live in Oxfordshire. Met my husband and moved up here. We used to live in Fulbeck, which is why I was at Lincoln Hospital. And then, we moved to this house, three years ago. But this village has always felt like my home, because of the links with my husband's family and stuff here. I have got a lot of friends here and so, it's a nice place to live.

DN: OK. So it wasn't a bad transition trying to move here then?

No, no well it was hard when I moved up when I changed areas because I didn't have any friends in the area. But I've got quite a big extended family in law. So they definitely made it easier. And I think, the more northern, it's not really that north but more north than where I

used to be, people tend to be a bit friendlier and open. I find it easier to make friends and meet people up here than where I used to live.

DN: Do you go back to Oxfordshire much then?

No, no, this is home, yeah!

DN: So, if we could talk about when you were first diagnosed then, how long ago was that?

Yes. I was diagnosed in February 2015, so two and a half years ago. It was an incidental diagnosis, I had a miscarriage, the second miscarriage of my life, the first one here in June of 2014. Because I was in the middle of wedding season with flowers, I didn't have time, to have time off work for the operation, and such, so I decided to go through it naturally, which felt like a bit of a mistake at the time. So actually, fortuitously, it meant that I had follow up scans, which then they found a cyst on my ovary, which they thought was benign, and I think they, I didn't realise at the time but they had tested my C0 125 at that point, it was raised, but at the time I was a smoker, and I had just had this miscarriage, they thought the hormones would defect it. So I did get referred to a consultant at Lincoln, who it took a while to get an appointment with him. I think I seen him in November 2014. In the meantime, I had really severe pains in my left ovary. Really, really painful. And so, when I went to see him, he was still of the opinion, that it was nothing to worry about, that it was, I can't remember what type of cysts but something that was fairly, so did I want to proceed further? And I said, I did, the pain is getting to a point where I can't manage my lifestyle. So they did some tests, they sent it off and did some tests, and it was cancer, it was stage 1, stage 1 C I think it was? So they felt that because, if the cyst had been on the outside of the ovary, if it had been removed on the left side of my body, and taken through my body, they felt that it was right that they treat it really aggressively, and because of my age and all that kind of stuff. And so then, after obviously talks and lots of other things, I decided to have both my ovaries removed and have a full hysterectomy as well. So I had that done at City Hospital in Nottingham. And then it came back that I got, biopsy, is that the right word? Then it came back that I had stage 1 A womb cancer, so that was good that we took it out. And then I had six rounds of Carboplatin and Paclitaxel (??), double chemo.

DN: Right, and how did you find that?

It was hard, I think with the cancer treatment, you do feel like you are on a bit of a rollercoaster and you just kind of go with it because that is all you can do. I think it was difficult living your life in three weekly sections. I suppose that is how I used to feel, so I was on a three-week cycle, and you would feel, I used to have terrible side effects which we did try and manage, but it's one of those things, I would have a week where I would feel dreadful.

DN: Could you tell me a bit more about some of the side effects?

Yeah. So I used to get horrendously constipated for over a week. Horrendously so. I would get terrible sickness. I tried various different anti-sickness tablets that they gave me and various different concoctions and the oncologist was always changing them but we never got it quite right. It did get a little bit better towards the end. I used to get pins and needles in my fingertips and toes, which again, he tweaked the dosage so that he brought it down slightly, he was worried about nerve damage in the end. Very tired. Get this sort of aching limbs, like pains in your bones, but very very tired, it sort of built up so the first round wasn't too bad, I was still fairly active. I can remember going in for the pre-chemo chat with the oncologist and saying, well, I am so tired. And he said, well tell me what you have been doing? Well I did a twenty-mile bike ride and I can't believe how tired I am! He literally just laughed. So, I would say until probably the third round, I very much became, walking up the field to see my husband was too far, I couldn't really take the dogs very far, I was just so tired. I lost all of my hair. That fell out after the first one and then I lost my eyelashes and my eyebrows as well. I lost all my hair, everywhere. Which had ups and downs, you don't have to buy shampoo, which is quite nice, or get your hair coloured, so yeah that was hard. I think eyebrows was the hardest, like a visual thing.

DN: Did you go to anything when you had the hair loss?

Yeah, I did. Yeah I went to Maggie's, they do the Look Good Feel Better. So because I had my operation at Nottingham, I became familiar with Maggie's so I did it there. And I did go there to the Look Good Feel Better. Happily, it happened, I was booked in on the Monday and my hair started to fall out on the Sunday. I had already decided that I was going to shave it as soon as my hair started to go. So, I shaved it off and the next day went to this thing which was fantastic. Really empowering. Obviously I was like a newbie, 24 hours since I lost my hair and sitting in a room, I had a scarf on and stuff, sitting in a room full of other bald women was really good, it was a bit freaky to start with, you think, oh no, I look exactly the same. But it was really empowering and to learn how to do things that could maybe make you feel a little bit happier about the way you looked, stuff like that, that was good. I also did, there is a reflexologist in the village, and a friend of mine said, have you tired reflexology, I used to get her to come straight after chemo, and she solved my constipation problems, so that was great, that helped a lot. It was just the sickness that I never really managed to get on top of and the tiredness I guess.

DN: What about now, what sort of follow up care are you involved with?

So now, I have just been moved, hooray, to six monthly checks, so that is very good.

DN: So before that what were you on?

Three monthly. So I was on, monthly to start with for the first couple of times maybe and then it went to three monthly. So I had an end of chemo scan, then I had another scan I think, that year before Christmas. Then I had my bloods done, I haven't had my bloods tested for probably the last two times I think. So yeah I just go and see the consultant at Lincoln, internal examination as well.

DN: And how do you feel in the interim period, is it something you don't really think about until the appointment is coming up?

I don't think about it now. I did. It used to play a massive part. I think when you have finished treatment and you sort of have to go and get on with your life, it is a very weird feeling because your whole life has been orchestrated by appointments and when you have to go for a blood

test and then all of a sudden they go OK, go and live your life…. ehh…what if it comes back? So I had a lot of problems with that, I also had to sort of then deal with the fact that I can't have children, the emotional impact of that. I had the menopause, that had massive implications and also within our marriage things had changed, both of us trying to get our heads around that and where we wanted to go in the future, did we want to adopt kids, all that kind of stuff. So there were so many different things, so I did have a really tough time mentally and I did go to Maggie's again and I had counselling. It would have been every week if I could have got there, but I was always too busy so I used to go every three weeks or so, for about a year, saw a counsellor, and that really really helped a lot. And then I also, I've done a lot of self-care really. So I have completely overhauled my diet, I don't have gluten, dairy, I have like irritable bowel since my operation and stuff. So I don't have gluten or dairy, I don't have meat, I'm trying to go vegan, but I'm not sure I can persuade my husband he could cope with it! But I have always been really active, I always do yoga, meditation, all that kind of holistic stuff, for my mind. So I take a lot more…

DN: So did you always do this, even before the diagnosis?

I always had a very healthy, active lifestyle but I did smoke. And I did do things like yoga and Pilates but I didn't meditate, I didn't really understand the impact of your mind on your body. And now I have read loads of stuff, I think there is a huge connection between that, so I spend a lot more time trying to sort my head out than I used to. I used to exercise to get fit, stay thin, or whatever. Whereas now I do it for entirely different reasons, I do it because it makes me feel good in my head, which I think is really important.

DN: That is very interesting. Could you tell me more about the meditation and things, is there a certain type you do?

I do, so I do, I go to a group meditation on a Thursday that is in Newark. Run by a lovely lady, who I found out about through a lady that I do my yoga with, and that's really nice. But then she and also my yoga teacher, shared an app you can get on your phone, headspace.

DN: Yes, I have heard of this.

It's great. So you can download it for free and then you get like ten, ten minute sessions for free and you can decide whether you want to upgrade or not. I have. So I've got my husband on it as well, he is quite stressed at the moment so he is on there, doing that.

DN: Has he found it beneficial?

Yeah. It's huge, it's massive, you can't believe. And I would have always thought hippy dippy sitting there going "hum…" I mean you do do that, don't get me wrong, sometimes, but not with headspace, that's just very much listening to someone's voice, quietly listening and it's all guided about visualisations and all different things and its great. There is another one called buddify which has got loads of two minute apps and stuff. You can say like, say for the headspace one, you want to do one for creativity, stress, anxiety, headaches, or whatever and there is like different ones for different things. My husband struggles with sleeping, so sleeping ones, he does those and they seem to help. So yeah, it has become a big part of our lives, whereas before it never was.

DN: And is that something you do every day then?

Yeah. Just for ten minutes, that's all the time we have!

DN: If you could tell me a bit more about work, you are a florist?

I'm a florist, I was a gardener and a florist when I was ill, when I was diagnosed. I do mainly weddings. So the wedding season is massive for me. This year we did fifty, fifty weddings, so it was a big year. I grow some of my own flowers, I used to garden for people as well but now I just garden for myself, and I don't have enough time. So through the summer this year, I worked about seventy hours a week so it was a bit full on. And I went back to work, after treatment, in hindsight, probably a bit too quickly, I was very keen to get back to work and get back to normality but I was so tired. And although everybody told me, I hadn't appreciated quite how long the side effects, in terms of tiredness and energy levels were going to continue for. So I probably could have been a bit kinder to myself there. But I did go straight back to full time like a month, not even a month, three weeks after I finished.

DN: So how long did you stop work for then?

I think it was six months.

DN: Six months. But you were really keen to get back?

Yeah. I never really, because I'm self-employed, so I never really completely stopped, I mean I did but I did the odd wedding and because I had weddings booked in for the summer I had to find somebody else to do them. To start off with, I realised it wasn't fair on them or me, I had a friend who was a florist, to take on all of my weddings, but if I felt well enough, I would go and help, so I never stopped completely but yeah I probably worked like one week out of three.

DN: And now you are back working as much as ever then?

Yeah, crazy hours, yeah.

DN: And you like that?

Yes.

DN: So I said at the beginning, this research is looking at something called self-management, if I was to say that word to you, does it mean anything to you?

Yes. So for me, self-management is about I guess, taking ownership of your own body and learning that you can impact it yourself, by taking care of yourself in different ways. So for me, it's taking the dogs for a walk, eating well, doing my meditation, doing yoga, doing that kind of stuff, that's what I think self-management is.

DN: And what about the yoga, where do you do that?

I do that in Newark as well. That's on a Tuesday night. But I also do, again, there is another app, it's an online thing, called movement for modern life, and I joined it as a subscription thing and you can do live classes, or recorded classes, anytime of day wherever you are, so I do that as well because that's nice. That fits into my lifestyle a bit better because I don't always have to be at a specific class, so that's good. And that good for my body. You used to get really obsessed when you have finished cancer treatment, I think most people would probably say the same thing, you get really obsessed about it coming back. Or every ache and pain, is that cancer! Every sing thing and it does become a bit ridiculous but I was getting quite bad pains where my ovaries used to be. You start thinking, oh! And everyone said, no its just scar tissue. It's not scar tissue; I know it isn't! It was, obviously. And then there is different ways, I have a yoga ball, it's about that big, which my yoga teacher showed me, we do a lot of that in yoga as well, it sounds ridiculous, but you lie over it and you roll on it, it helps to massage your insides and it stops my pains, my scar tissue pains, so stuff like that really, is useful.

DN: So when you were receiving treatment, were you happy enough with the care and things that you received?

Yes, I was, really.

DN: So who all was involved, did you have a Macmillan nurse or anything like that?

No, I didn't. I had just the oncologist, cancer nurse at Lincoln Hospital, that was it really and obviously my consultant from Nottingham who did the op.

DN: And did you feel quite well informed about what was happening?

Yeah, yeah, I think they explain everything and I think it's whether or not as a person you take that all on board. I think as well, I started taking someone else with me to any meeting because you can't take all the information in, you think you are going to but your brain only remembers certain snippets so my mum in law used to come a lot with me so I could remember everything that we discussed. I can't fault the care that I had, they were fantastic, there was always someone at the end of the phone, you know when you are having a crisis because you are constipated or whatever. But also my GP, absolutely fantastic, they were fabulous, they would

always get me in within seconds if I needed to, so that was really nice to know that was there as well.

DN: When I asked you about self-management, you said it was about taking responsibility for your health and things, is that something you think, even before with the cancer, you would have been familiar with or you would have engaged with?

Oh…Probably if you had asked me then, I would have said yes, but I think looking back on it, I don't think I was, I think I became very reliant, as a society we are very reliant on doctors to make us better. We have to be able to take a pill and then it will go away. Now I very much feel like there are other things that we can do every day that help to keep our blood pressure down, or our stress down, whatever, that will then have a positive impact on the rest of our health and body. And I was a smoker, I have given up smoking which is a big thing.

DN: And when did you give up smoking?

Oh…don't ask me that, after treatment! I have been giving up smoking for a year and a half. I was very naughty and I refused to give up when I was having treatment because I was cross that I felt that everything was being taken away from me and I was not giving that up. So yeah, that was naughty, but I have given up now.

DN: And what about alcohol, would you be conscious of how much you drink, is that something?

Yeah, I still love a wine, I won't lie. And I did say to my oncologist, can I drink through chemo. And he said, not really, but the odd one isn't going to hurt you. So I did drink wine through chemo, not the first two weeks but certainly the last week before my next round, I might have a few. Which probably in hindsight is not ideal, but I was kind of the opinion, whatever gets you through the week. But still, I like a wine, I like a gin. I am conscious, my husband doesn't drink at all, I am conscious of the impact of that on my mental state as well, that was definitely made worse if I drank a few too many wines the night before, so I am conscious that plays a part for me, so I try to moderate myself, a lot more than I used to.

DN: And what about your diet, could you tell me more about that, you were saying about vegetarianism/veganism, is that something you were conscious of before?

Yeah I was always very healthy, I used to be vegetarian but then I started eating meat again. I have always been fairly health conscious but the gluten and the dairy thing was a whole new thing that started, I tried to do it at the beginning of treatment, when you first lots of people send you books and you are like, maybe I should do think, maybe I should do that? And I just didn't get on with it. But then I had terrible IBS type thing so then I cut out gluten and it had an immediate effect, then I cut out dairy which then forces you to look at other ways of getting those nutrients and also not relying on all the pre-processed stuff because that's not very good either. And yeah, so, I'm going to go vegan in January, just don't tell my husband! I've only just got him eating a vegan curry so we won't go too far! So yeah, so know I try not to have too much sugar. I've got a bit of erm, what's it called, when you have like a, it's not hypo but your blood sugar drops, so I have a bit of that, anyway, so I have to be careful with sugar, I would love to sit and eat a bag of sweets but I can't because I would feel dreadful, so yeah very conscious about all that sort of stuff but my husband still eats plastic ham and plastic cheese, I don't!

DN: So where would you go for shopping and things like that then?

Food shopping? Place, a shop, or location?

DN: Just in general is there somewhere locally you would go for fruit, vegetables, or would you go into Newark?

Yeah we do tend to. There is Co-op at the top of the road, which is good for those last minute things, it was great when I was poorly because you could still go the shop, we have a doctors, a library, so that does make a difference when you can't get out. But yeah, we would always go to Newark, there are various different supermarkets we would go to there, so yeah, go and do a big shop.

DN: So thinking again, you have mentioned the yoga, the meditation, what other things would you say you engage with that help you manage your health?

Eh…I don't know really? I think having a positive outlook. I really believe there is a massive link between your mental state and your body, so I think there is a lot more we can all do about taking care of our minds really. I think my job is quite good for that, as well, it's quite, so like mindfulness and all that type of stuff, when you are doing flowers or gardening it is quite mindful, so that does help. I like spending time with positive people, people that don't drain you, that is really important. Making the right decisions with people in your life and yeah just try and have a nice happy, calm life.

DN: And did you ever go to any support groups or anything like that?

Yeah, I do, funny enough I was there last week. There is a support group, I forget what they call it now? It's for women who have had ovarian and/or breast cancer I think. And it's run by one of the cancer nurses from Lincoln Hospital, she is retired now, and they meet once a month. I think the thing I struggled with is, because I am younger, a lot more people tend to be over fifty who have had what I've had. So I used to struggle to find people I could relate to. So I spent a long time feeling I had more in common, I think that might be why I get on so well with my mum-in-law, I've got more in common with her sometimes than I do with friends my own age. I have gone that sort of leap; I am like fifteen years ahead of them in my body. So I do think, I think Maggie's said there was a support group there but it is just too far to go every week to Nottingham at that time of day, the traffic is pants, and fitting it in your schedule, so I think there is a gap in the market for something like that.

DN: And when you went to this, did you find it helpful?

It's always nice to be around other people that know what you are talking about. And it's always nice to be around other people that understand when you say something what it is, what the repercussions are. And I went back there, Thursday, last week to do, I've done it before there, do like a demo, and then they make stuff. So last week we did Christmas Wreaths and it was actually nice to go back because I hadn't been for two years. And I realised how much I have changed, and how much I have accepted my situation. When you talk to other people who are more recently going through that kind of stuff, you realise that you have got advice to give

them and you have got positive things you can say to them, that they can then implement into their lives and it might make their lives easier.

DN: And did you go to anything like that when you were having treatment?

No. Because I was so tired, driving was a bit of a chore to be honest, I didn't trust myself to drive. There wasn't anything in Newark, I did look. I did join Maggie's online for a bit, and I think at one stage, one of the nurses at Lincoln said they were going to get an ex-patient or something to ring me but that never happened. And I think that is something…I did something like that with a miscarriage thing, there is a charity or something, you can register and then somebody will ring you has been through that situation, you can talk to them, it's all anonymous, you can carry on with that if you feel it helpful. I think definitely, maybe there is something like that, but something like that would be really helpful. There is also a friend of mine showed me on Facebook, there are quite a few cancer support groups on Facebook. Some of them are really helpful and some aren't so helpful. But there is also one called The Daisy Network which is for people who have had early menopause but not necessarily cancer related. So some people can have menopause in their early twenties or something because it's something to do with your ovary, there is like a special medical term. I found becoming a member of that really helpful because there are loads of fact sheets and about how it affects you when you are younger because obviously there are loads of sexual implications and tonnes of stuff that everyone takes for granted when you are our age, my age, that change, and there is no, if you read the stuff about menopause, it's not necessarily relevant to someone my age. So reading all that was really helpful. I printed the factsheet off and showed it to my husband because it's hard to deal with the different things that are going on all the time. And I read it, and realised that was me, it exactly described me, I showed it to him, and he said, why didn't you say? I've been trying to say! So things like that are really helpful but I do feel like sometimes you have to go really looking for them and perhaps if you are not that way inclined it's not always easy to get the information.

DN: And with your husband, was there a strain on the relationship when you were going through this?

He was fantastic during the cancer treatment, absolutely fantastic, could not fault him. Never once looked at me like I looked, I was really conscious of the way I looked without my hair, never once looked at me any different, really supportive. I think we struggled, when I was struggling mentally with the child thing. So I had to sort of had to go through a grieving phase which he didn't understand, cause he had already kind of done that, I hadn't cause I was going through cancer treatment so I was focused on that and then when I finished cancer treatment I was like, oh, I can't have kids, my friends were having babies, you feel like they are all around you. So we struggled then because he couldn't see my perspective, so it was trying to get us onto the same page, which we are now. But it has taken two years, so it's just not easy.

DN: And was there anything in particular that maybe helped with that?

That Daisy Network thing I mentioned, that was a massive turning point for us because I had been trying to explain how I felt about, the menopause is like one big PMT (premenstrual tension) sometimes. Hot flushes, tiredness, anxiety, mood swings and all these different things. And you try to explain, well most women understand, but partners, husbands don't always. He really didn't get it but when I showed him this thing in black and white, which is what I had been saying to him, but because it was like an official document, he was like, oh, ok then, that's fine! So as soon as he realised that I was sort of normal for what I was going through, and I wasn't like some kind of freak of nature, he started to accept it a bit more, I think really. And we found ways that we could kind of navigate. And I think he gave me a bit more of a break, he was a bit more understanding. Whereas before he wanted me to finish cancer treatment and go back to how I was before but that wasn't going to happen because I was a different person, I suppose, really, not through choice just because of what happens.

DN: And you were saying about you wider network, in terms of family, support and things, could you say a bit more about that?

So mum-in-law is probably number two supporter, I live in her garden! She used to come and see me every day just to check I was all right. I see her most days anyway but she would always nip by, she would offer to go to the shops for me, help clean, do my washing, all that sort of stuff. She was just there, all the time, for anything. She would go to appointments with me, whenever anything, when I found out my chemo date, I was like, oh no, I'm starting on

Monday! I ran straight down there and she was just great really, she is like a best friend. And then I've got my friends who are all fantastic, my friends from where I used to live would come up regularly, at least once a month to see me and then new friends round here. In the village itself, I made friends that year really within walking distance which is nice, so there was always someone around. Very rarely did I have a day go by where I didn't have a visitor just popping in to check I was all right. Often, I would be sitting here, because there is a footpath that goes up there, people could see if I was asleep or not, so they would come to the window, if they could see I was asleep they would leave me, if I wasn't they would come in and see me.

DN: And was that nice for you to have that or did you ever want to be on your own?

Bit of both. Yeah. I think it was nice but absolutely sometimes I wished I just had a room and could be on my own without any of that so I didn't have that, that did used to drive me a little bit crazy but in the main, it was positive I would say.

DN: So you do the yoga, meditation, what is your prime motivation for doing these things then?

They make me, it makes me feel good really, it makes me feel better, feel calmer in myself, happier, yeah, it just helps me go through life a little bit easier I suppose.

DN: And with the cancer and things, you now have your six month check-ups, do you feel confident at the minute that if anything were to come up, you would know where to go, know who to contact?

Oh, yeah, absolutely, yeah. I have still got the main numbers on my phone, if anything, I can ring straight away and I know I can get through to someone.

DN: So who would be your first contact if anything were to happen?

Eh…I would probably ring the cancer nurse, it's not Heather now because she has left, so I don't know who my cancer nurse is, but I would ring that number first and then I would go to my GP up there. He knows all these things. Normally knows, knows me well enough to say,

you know, we have done these blood tests before, you are OK, or you need to do something else.

DN: And is that something good for you, the familiarity?

I love it. I love that I don't have to worry about saying anything, I don't even have to say my name when I walk in, they know me, and so I really like that, it just feels like it's safe.

DN: And can you think of anything at the minute that prevents you from doing anything you like, or prevents you from managing your health?

No. Just sometimes time pressures, doing too much work, same as everyone else.

DN: And do you think you shouldn't be doing as much work sometimes or do you like to remain busy?

Ehhhhh……...pass! I think I use my work as a reason to be really. I suppose, I think I struggled a lot with, what is the point of me, if I can't have children, obviously, scientifically I was put here to reproduce and what is the point if I can't, and it took a lot of time to work out with my counsellor that it is like a ripple effect, you might touch people in different ways. So for my work, it is very much part of that, I deal a lot with brides and grooms, I deal with lots of different people and I suppose I make them happy, hopefully. So that is part of helping me I think, so that's why I think I do it so much.

DN: So you find you are a lot busier in the summer then?

Oh yeah its mental, it's like awful! My husband doesn't see me for four…the only reason I eat in the summer is because of him, and the only reason he eats in the winter is because of me, so we kind of balance each other out. So yeah, I'll go quiet, January, February, I don't really do anything at all.

DN: That must be quite nice too?

Yeah. Yeah.

DN: And are you busy at the minute?

Ehh…yeah busy doing like paper work, boring, emails, quotes, accounts…dull stuff like that which I really need to get sorted before Christmas season starts.

DN: So yeah, I said at the start, we are looking at differences between rural and urban areas, so how would you characterise where you live?

Ermm…I would say its rural, yeah. We are, although we are very rural, we are very close to the A1 so it's quite quick in the car to get to lots of different places. But the village itself is quite large, we have quite a lot of amenities, in the village I used to live in before, we didn't have a shop, a school, a pub or anything. Whereas this one has all those things, has a library, has a post office, one of those satellite ones, twice a week. So you could pretty much, if you had to, exists here, quite happily without having to leave the village, which I think helps quite a lot.

DN: Well what sort of things do you engage with locally here then?

Eh…so not so much now, but when I was ill, I used to go to the library twice a week, I'd always go to the shop every day. I was at the doctors however many times a week with various different things, so yeah, quite a lot I would say.

DN: And would you say living here has a positive impact on your health?

Yes, I would, yeah, absolutely. There are lots of nice walks, I've got a dog and I was saying to my friend the other, my whole life I wanted to go somewhere that I could go for a dog walk

without having to go into the car, I have that now. We can go for four different types of walks from here which is lovely.

DN: So how many dogs have you got?

We've got three! We've got three cats and three dogs. We have two old dogs and one four-year-old Labrador that we have just, we dog share with my father-in-law. My favourite walk in the morning, is down by the river, there is a place called the homes, it's just the flood bank or the river. And in the summer, there is cows on there so you can't really walk the dog, well you can but it's not as much fun. So now you can take them off the lead and they just go flying, they have a nice time, it's about three miles, round trip.

DN: So you walk them in the morning, do you walk them in the evening as well?

Yeah. Well I walk them morning and evening, then my father-in-law walks them, they have so many walks, walks them at 11 o'clock and then again about 4 o'clock. So they have four walks a day!

DN: Well they must be happy dogs! So is there anything you can think about living here that impacts your health negatively, or how you manage your health?

I suppose sometimes, the lack of privacy. It's less to do with the area and more to do with this house specifically I guess, really. That does stress me out sometimes but other than that no.

DN: So you have a lot of friends that live close to here?

Yeah, I do now. Yeah I have made quite a few friends here so it is quite nice. Doing the flower things as well is quite nice, you meet a lot of people in the village. So yeah, I feel very much like a villager, which is quite nice. I am not in like the "inner sanctum of villagers" because that would do my head in but I can certainly walk around and know people and it's nice.

DN: For your business then, where do you advertise for that?

Eh mainly like wedding orientated blogs and stuff, but I do advertise, there is a local magazine called unity, I do advertise in that.

DN: So quite a lot of your business comes from the East Midlands then?

Oh yeah, yeah, always. Yeah it's like only in the local area but for weddings I do travel up to an hour's drive time that could take you to Peterborough, Nottingham or Louth, all over, so yeah.

DN: And is there anything on a local level, or even on a national level that you think is missing for someone who has went through something like you have?

Yeah, I do think, some kind of support network for younger people, that is accessible nationally, that is not area specific, so something like I mentioned, like a website that you could go on, that could then put you in touch, you would have volunteers. So if that existed, I would happily volunteer to be one of the people that would ring people up, that has been diagnosed or whatever, that is going through those things because I don't think there is really that much out there for people with cancer at this age. And then the repercussions of that, so I know I had the operation to remove anything but if you have chemo, that stops you from being able to have children anyway, so that's quite a wide audience of people. So I definitely think like a younger, under 50's kind of thing.

DN: So even like telephone, online, email?

Yeah and I think telephone and email is probably better for our generation anyway, because that is something we all tend to deal with better. And everyone, even when you are ill, everyone has busy lives and you probably want to do it when it suits you more, so I think that would work better, definitely. And it would be nice, I'm very lucky, I have a very close friend now, who has had the same cancer as me, she had stage III, so we have got each other and that has made a massive difference to me, having that person that I can talk to, about all those sorts of things that only she really understands. And other people are very nice and try to be very understanding but ultimately they don't know what it feels like. So sometimes, everyone thinks you have to be really positive, of course you need to be positive but you don't have to be

positively beaming and happy all the time, you are allowed to be cross, and angry, and sad, or whatever, some of the time. So it was nice just to have her and I think that is important relationship for anybody that is going through that, so I definitely think that is something.

DN: So how did you meet her?

Through a friend. She lives in the village but I didn't know her. But a friend, who is both of our hairdresser, and she told me that she had a friend who had just been diagnosed, would I be prepared to speak to her if she wanted, and I said, yes of course. I texted her and knew she was starting chemo so I just went round her house with a chemo survival kit, things that helped me that I thought might help her. So that's it really, we became friends from there.

DN: So maybe just to finish do you have any health needs or anything that aren't being met at the minute?

Eh…I don't but I think because I managed them. I guess everyone is still finding out how to live with cancer because it is becoming more common for people to survive and live their lives going forward. So I know there is probably a lack of information about what to expect going forward. But I think things like, the stomach, diet, a lot of people I have spoken to are in a similar boat to me, they can't now have gluten, their digestion system has completely changed. I think if there are things.

DN: So did you find with this information that you were going and finding it yourself?

Yeah I'm not even sure it even existed. I think I just made my won suppositions really. I've decided that's what it is, that's what I'm going to do, and that's what makes it better. But if people don't have that information or aren't prepared to try something different without someone saying, this could do this, or this could do that, then I don't think they would necessarily. I think you have to be a certain type of person to say, OK, I'm going to do this and see what happens.

DN: So do you think of people that maybe aren't of that type of mind-set, to be very proactive, that information…

I don't think it's there.

DN: You don't think it's there, no? So you think there needs more of an effort for these things to be provided?

I think living after cancer, there is a big, I think there could be a lot more. There is so much information about diagnosis, chemo, it's fantastic, Cancer research, Macmillan, you can find anything out about anything, any word the oncologist has used, it's brilliant. But then after, nothing, almost. You can go on, Cancer Research, they have things like latent side effects and things like that, but there isn't really that much information about how to manage yourself going forward. So I definitely think a holistic side of things.

DN: And did you ever have a needs assessment or anything like that?

I don't remember having one.

DN: No, you might not have. This is something now that Macmillan are trying to roll out, where people get offered a needs assessment at different stages in the cancer journey, so perhaps not at diagnosis, but before treatment, during treatment, after treatment, and then into follow up care. So there is a record of these needs. Then that is meant to link in with the GP, there would be a treatment summary, so to improve the relationship between the oncologist and the GP, obviously everyone is very different, but they are certainly trying to make progress with that side of things.

OK, that's cool.

DN: But yeah that is quite recent.

It's all just new isn't it?

DN: Is there anything we have left out then?

I have probably talked enough!

DN: OK, great, thanks.

INTERVIEW ENDS

APPENDIX 25: EXAMPLE OF CODED INTERVIEW TRANSCRIPT

<Internals\\QUAL12> - § 1 reference coded [100.00% Coverage]

Reference 1 - 100.00% Coverage

QUAL12

Qualitative Interviews: Self-Management in PLWABC in Rural and Urban Settings.

Face-to-Face Interview; Participant's Home; 27/11/17

Audio File: QUAL12_271117_ID003.Wav

Interviewer: David Nelson, University of Lincoln.

Participant Information: QUAL12, ID003, Male, 62, Head and Neck Cancer, Resident in a Rural (F1: Rural Hamlet and Isolated Dwelling) Area in Lincolnshire.

DN: So to start, if you can just introduce yourself please?

Right, OK. My name is (removed). Retired deputy head teacher. Diagnosed with base of tongue cancer, Christmas eve, three years ago. And I had surgery in the January that followed to remove a chain of lymph nodes.

DN: And where did you have the surgery?

At Lincoln. Yeah. That was followed by thirty sessions of daily radiotherapy and six lots of chemo, one a week. So obviously a very trying time for myself, my family.

DN: And what about the side effects and things?

Well very dry mouth, sore throat all the time. I still have a sore throat now. It was quite radical radiotherapy. I've got an under functioning thyroid, as a result of the radiotherapy, so I am on full time medication for that.

DN: And the chemo, what about side effects with it then?

Eh, I managed I think the first two weeks, I didn't really feel anything, week three came in and basically my family took over because I was not in a good way really. I had a stomach tube fitted before the radiotherapy and chemo started, which was pain in the arse really. So, tried doing overnight feeds, not very successful. I found that psychologically, I found it very difficult to deal with.

DN: So you said about your family then, who do you have to support you?

Well I've got my wife here now. All three of my children live away. Daughter is at University in Cardiff, she is a design engineer, I've got a son who has got his own company, he is a software developer and my youngest now is in New Zealand, two years in Australia next. So, yeah, no, when they weren't having to work, they came here and drove me backwards and forwards. I think the other psychological effect at the time was the journey to and from, 80, 90 miles. And the appointments were never consistent, you know I could have a late afternoon one and be there for eight o'clock the next morning. That was not great.

DN: And how long did you find you were spending at the hospital when you were there?

The chemo was about three hours in total but I had radiotherapy sessions at the same time. The radiotherapy was ten fifteen minutes max, each session. And you know, the staff there were brilliant, really, really, really good. No complaints there.

DN: So in terms of staff, who all was involved then?

There was an oncologist, ear nose and throat consultant and then the radiologist in the department. I think the most shocking thing was arriving for the first session, just how rammed out the place was and that was pretty horrible, really. So yeah, I've got no issues with the treatment. The only issues I've got is about waste but, that probably doesn't come into your scope, not NHS waste but the feeding stuff.

DN: Feel free to tell me about that?

We had hundreds of bottles of liquid feed that were left over. There were just hundreds and hundreds of these bottles of this stuff that they just kept delivering and delivering and delivering. And I was expecting them to take it away. But, no. And then we tried old age peoples homes, we tried charities, none could take it off us, because…

DN: And why did they say?

They said because they couldn't say how it had been kept. The instructions were quite clear, keep it at room temperature. Looking at the price of those things, I mean they were thousands of pounds. I just thought criminal waste, of resources really. I mean it could have been packed up and used as emergency food relief or whatever. You know, high calorie stuff. That was a negative side effect if you like, the cost. So I finished the treatment in April 29th 2015, in total. I had six week reviews. They were later moved up to three months.

DN: I'm assuming for these reviews you had to go to Lincoln again?

Yeah, yeah. I don't think they had the facilities in Boston. So yeah, touch wood, I have been all clear. But not all clear in the sense of, you know what I mean, five years and whatever.

DN: So what sort of follow up care are you involved with now?

Basically bloods before the appointment. And then, really, it's a case of having an endoscopy. So I have that and generally an examination of the neck, throat, gums, tongue. I had some problems swallowing a while back.

DN: How did your diagnosis come about?

My brother had a lump in his neck. And it turned out benign but this thing wasn't going away, you know what I mean. My GP or a locum GP sent me off for an ultrasound. They said then,

you've got a blood supply, these things come and go, it could be a cyst. So anyway, it got bigger, and I went to see my own GP, my regular GP.

DN: And where are they based?

That's in Gosperton, just up the road, who is phenomenal. And he gave me an examination. He said, (name removed), you've got cancer, there is no easy to tell you. You are going in, in two weeks. Anyway, that two weeks ended up being forty-two days before I got an appointment in Boston. And this was, as I say, Christmas eve. And they rang us on the way back and said, you need to go to Lincoln, because it was an MDT, obviously who discussed my case. Got it confirmed there. Then it was go in, surgery side of things, stay in hospital. Erm, and then eh, having the mask fitted and all that sort of unpleasant stuff.

DN: So you had the surgery first…

Surgery first, then six weeks later, that removed the lymph node chain from my neck. They did a biopsy of the carcinoma, to get a confirmed confirmation. So I was pretty much at stage three with the lymph node side of things but you know I had a complete scan and there was no signs of any other lymph node…had the treatment, six weeks later, the chemo, radiation started and then it was I think, about six months later, I was sent to Nottingham for a PET scan which came back OK. And then it has just been the follow up reviews.

DN: And how do you find the follow up reviews?

I get on well with the… the top man, there is a couple of the consultants that I have had trouble with.

DN: And why is that? Do you find it is hard to communicate with them or is it the way they speak to you?

The way they speak. I think you tend to get, I don't know, but you see so many people, many people are ignorant of their condition. But, I am fairly intelligent, I know what is going on,

just speak to me, you know. And so a couple, really talked down to me. Whereas the head man, we have a conversation, you know, and he is excellent, really really good. I have not seen the oncologist since, so I am presuming as I am coming near the end I will be sent off for another scan of some description. I don't know. That has not been explained. So I think side effect wise, it was psychological, in the sense that I needed something to focus on. And I kept asking for the MRI pictures, just to show me, where and what, and how, I was interested in the technology and how they were going to do it or, but obviously I think medical negligence was high in their minds, so I never got to see them. I suppose in a way, I was expecting the worst outcome. I am fairly, glass sort of half full sort of person. So the reviews, I've got another one on the 6th December and I can get quite depressed.

DN: Leading up to the reviews?

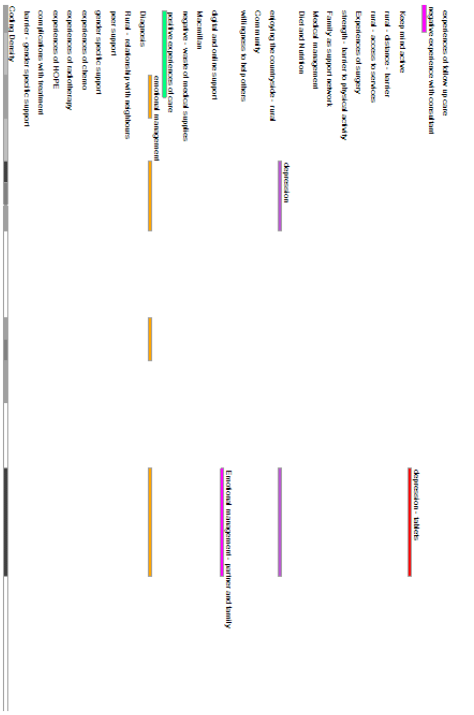
Leading up to, yeah, I sort of go into myself a little bit. But, you know, it's a pretty scary thought, you are going to be re-diagnosed or whatever. You come out feeling elated when they say, you are all clear! But you know, it's always on the back of your mind. Don't not think about it always.

DN: So it sounds like the emotional side has been very difficult for you?

Erm, not to the point where I have had to see a psychiatrist or psychologist. I think even just the journey times, the length of time treatment taking, you know, what have they missed. I mean yeah, it has taken its toll on my family, it has taken its toll on me. I have been depressed. I am on anti-depressants. Not huge doses but I have been, since I have been released from hospital really.

DN: You said at the start you were a deputy head teacher, were you retired when you were diagnosed?

I had retired in the September before, sorry in the July before.



DN: So you weren't working at all then when you were diagnosed?

No. No.

DN: OK. So I said at the start, we are looking at this concept called self-management, does that word mean anything to you?

Ehm, I went on a cancer survivors course run by Macmillan.

DN: Where was that?

It was in Bourne. And aspects of that were quite useful. Mindfulness and stuff (laughs lightly) didn't do anything! I don't want to smell a cherry before I eat a cherry you know! But you know, at that time, eating, well eating still is an issue for me. At the time, I had lost four stone, five stone. That's done me no good because I was also a type two diabetic but I don't have diabetes anymore, thanks to the weight loss I think.

DN: So you said about this course, what sort of things were good about it then?

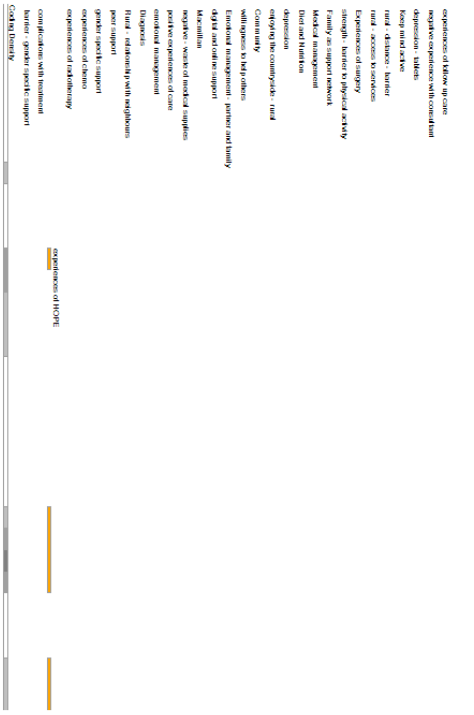
I think the opportunity to…

DN: Was this led by a CNS, or a nurse, various people?

Eh, one volunteer who had been through cancer herself and a CNS yeah. Six people on the course, three men, three women. Some aspects were difficult to really get involved in, you know, 'how is your sex life?' sort of thing. I don't really want to discuss it really. The mindfulness one drove me insane!

DN: So were these individual sessions then?

Yeah, six different sessions tackling, relationships, diet, fitness, mindfulness and a general session of input, what to input at the end sort of thing.



DN: So did you find any of the stuff around diet useful?

I did yeah. Because there was a Macmillan recipe book which we tried. I still can't eat bread, still can't eat meat. Which is no bad thing in a way, that I just eat and eat and eat and eat and drink and drink and drink, and not put any weight on at all, so that is positive, really. Yeah, so I have three dogs, so that is walking for an hour, hour and a half every morning.

DN: So do you walk them around here then?

Oh yeah, over the fields, into the woods.

DN: You are well placed for it here aren't you?

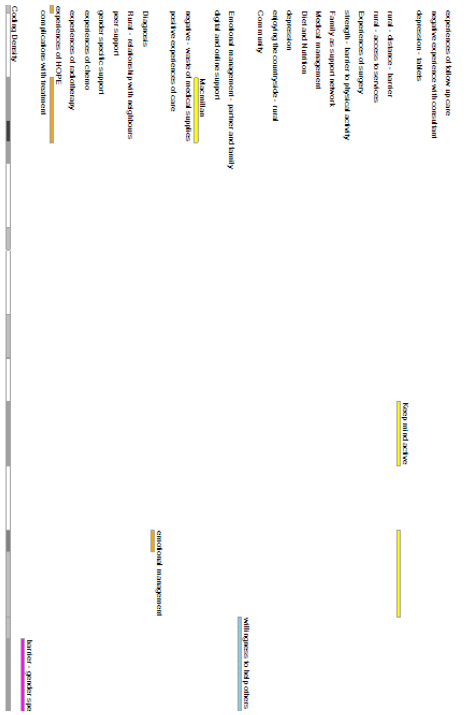
Yeah, absolutely! And I do a fair amount of just craft woodwork really. Making bowls and things.

DN: Is that something you have always been interested in?

Eh, I had to have something to do when I got out of hospital. I enjoyed turning wood at school, when I was at school. I had been talking about it. So, yeah, reading, the old gogglebox. Laptop. Family history all that sort of stuff.

DN: You say you had to keep busy…

So I didn't dwell on the situation, really. Plus I was driving my wife mad because she works from home most of the time and we needed to have some space apart, really. Yeah, id come from a highly stressful, very busy, working life. 39 years teaching. And erm, need to keep the old brain going, you know what I mean. Funny when I hit 60, my doctor said, I am going to have to give you the dementia test. Bugger off! [Laughs]. So, I think really, from a management point of view I would like to have given something back to other people. And I made enquiries with Macmillan and the GP because support for men, is pretty dire, pretty dire. I knew from the lady who used to come and change my rig. She was not a Macmillan



7A

person. I knew that there were over 40 between here and Peterborough with similar conditions to me, at various stages. Of either, late diagnosis, some in not such good condition. But there is nothing, nothing at all.

DN: By nothing, do you mean sort of support groups, or?

Well support groups, you know the men in a shed that is what I would like to do, the men in a shed bit and then, teach other people, get skills from different people, get involved have a conversation because I think, although, your wife and family know what is going on, erm, it is not always easy to have a conversation like we are having now. In fact, I don't think we have ever had a conversation like we are having now.

DN: So is that something you would have liked when you were going through treatment and after?

Yeah. You know I joined a Macmillan Head and Neck Cancer Group. I still do that.

DN: Is this online?
Online yeah.

DN: So where is that group?

I don't know where it is based?

DN: No I mean, where do you go on to join it?

Macmillan website.

DN: And how many people are on that?

Hundreds.

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DN: Is that something you go on quite regularly then?

Yeah when I read comments from other people with similar issues to what I have and had, I just put in my two penny worth. Things to try eating for example, what makes it easier. The sorts of thing. Everything, because tea, coffee, everything tasted like battery acid, for months and months afterwards. So I rediscovered coca cola. Which I had not drunk since I was a student really! The fizzy bit. It helped. So the ambition was, when I was fit enough to travel. One of my ideal meals is moules frites. So my wife and daughters took us over to France to a place where we had been before and we had a lovely week, eating moules frites.

DN: Great, where about in France?

Erm down near La Rochelle. Place called Puy du Fou which is like a historical theme park on a massive scale. Historical enactments. That helped. My girls were absolutely devastated when we told them. That Christmas, because I had been diagnosed on Christmas eve. Having the whole family here. That was tough, yeah, couldn't break that sort of news.

DN: So did you wait until the after the New Year then?

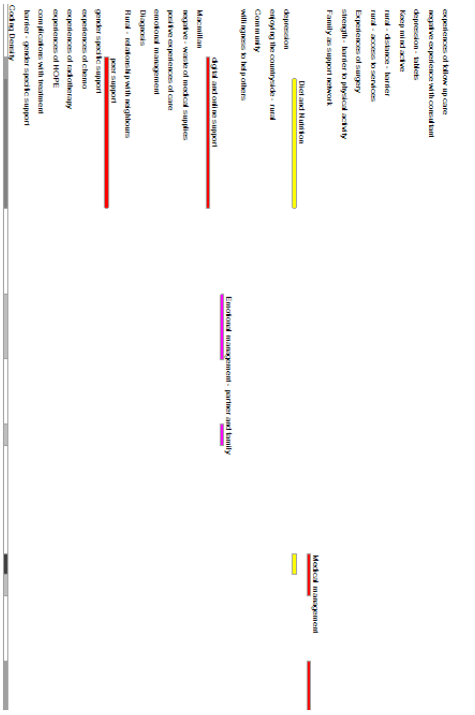
Yeah. Yeah. Also had to tell me mum. So yeah, that's when all that happened. So anything else self-management wise?

DN: So can you think of anything that you do, you have mentioned the woodwork and things, any things that help you with managing your health?

Well I mean dog walking, cycling, the diet is pretty good. I would like to get rid of some of the meds that I'm on, but. Stop with them really.

DN: The meds, do you mean the meds for depression?

Yeah. Well the thyroid thing is not going to go away, I have accepted that. I'm still on treatment for high blood pressure. And my blood pressure is like super low now! Again, so,



yeah. Time for one of those friendly GP chats. "Come on, [GP's first name] I'm sick of taking 14 tablets a day, really!"

DN: So is that how many you take a day is it?

Yeah, well I have to break two up because they are so big, I can't get them down my neck. So I have to break them into quarters. So it totals fourteen in total!

DN: And so do you have any side effects with the meds that you are on?

No.

DN: Can you think about anything that prevents you from managing your health?

Not really, no.

DN: So at the minute do you feel confident in taking care of yourself?

Yeah, yeah, absolutely.

DN: In terms of the cancer, follow up and things, do you feel well informed?
Yeah. Plus, a lot, I have stayed away from Dr. Google.

DN: And why have you stayed away from that?

Erm, I used it, to try and translate the letter I got, because I didn't understand the stages?

DN: OK.

Erm…you know, I think there is always a gold standard of treatment, pretty sure I got it. I didn't want to know about the success rates or anything like that. Five years…all that sort of stuff, don't want to know.

DN: So you stayed away from that sort of stuff?

Absolutely. Yeah.

DN: So whatever you were told, treatment wise and things, it sounded like you were interested in how things worked but you wouldn't really go beyond that then.

Yeah. No, no, no. I would question them. Is there an alternative? How long have I got to take this medication for? What happens four years down the line, five years down the line? How the follow up progresses.

DN: So asking these questions, do you feel that managing your health is your own responsibility?

Yeah. I got myself into this mess in the first place. Cigarettes, alcohol.

DN: Right, OK. Were you told that this was the cause?

Yeah. Well probably. 99.9%.

DN: And is that something since, have you stopped smoking?

I have a vaper that I use. And I like a glass of wine. But, I was drinking a bottle of whiskey a day, at one point. Don't have any spirits at all. I prefer beer. Well couple of glasses of wine at night with something to eat, you know, probably terribly bad for me, but who gives a bugger!

DN: So, I said prior to the interview that we are interested in where people live, so imagine if I hadn't been here, how would you describe here?

Well this is, it's called South Holland. Very flat, very rural, largely agricultural. Little in the way of large settlement. This village is very quiet indeed. Spalding is five miles away. We have got local services in the next village up. Quiet.

DN: And do you like it here?

Yeah. Yeah. Wouldn't want to go back to a town or city.

DN: Thirty years is that right?

Yeah.

DN: So you have lived in a city before?

Oh yeah, Northampton. London when I first started teaching.

DN: And why did you move here, was that for work?

Erm..I had got a job in Peterborough and we had a very finite budget. And so this place cost us 58k. But it was, not as big as this now, and no heating. Roaring fires. But fortunately myself and my wife have had a good standard of living in terms of income and we have been able to do things.

DN: And do you engage with anything here locally, are you involved with anything in the community, or things like that?

Sailing. I was Commodore of the yacht club for three years.

DN: And do you not do any of that anymore?

Physically I have just not got the strength, the upper body strength. Which is one area that my friends who are triathletes keep on saying when they come down. Bloody well, we are the same age, they have just done world championships for veterans, and they say get something

done about getting to the gym? Ermm, [laughs] you know? Or swim or something? Nah. It is something that I recognise I need to do, but getting the motivation to do it.

DN: And why do you think you are lacking that motivation?

I'm physically not as strong. I don't want to go through the no pain no gain type regime. You know, the garden keeps me occupied although you wouldn't know to look at it. Yeah, it's something that I have been mulling over for the last few months. But there are no free gyms around here. Its not something I would want to do on my own, you know, buy a set of weights. And it's really quite expensive.

DN: So, if you were to go to the gym, where would be the closest gym?

Erm, there are a couple, in town, in Spalding.

DN: So living here, can you think of anyways it impacts on your health positively?

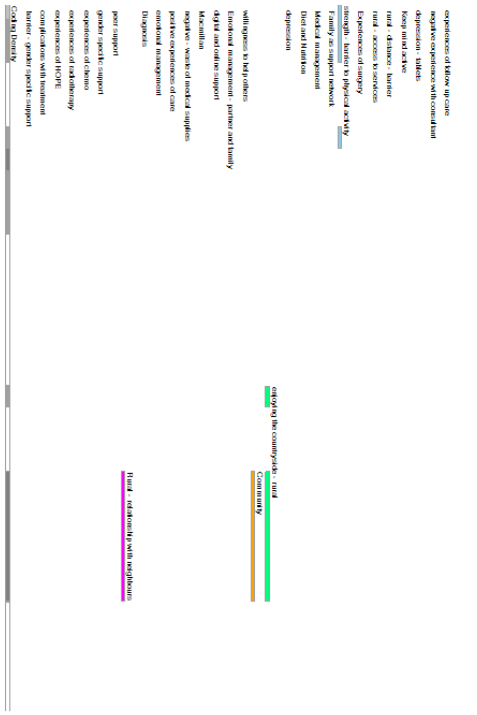
Erm, yeah, big skies, peace, tranquillity, most of the time.

DN: So you like the countryside?

I like big open, wide open spaces. I miss the hills a bit. We do the Lake District every year, couple of times. South Wales to see my daughter. So I suppose really, you aren't looking over your shoulder all the time. We've got five policemen that live, they are all neighbours, they are all police officers! So the local villains know who they are! They stay away. You can leave your car open, I have even left the house open on a number of occasions at night. Never had anything stolen, never had anybody trespassing, you know.

DN: So you feel quite safe here?
Safe. It is.

DN: Do you know all your neighbours then?



You know you can call on them if you need to. The one that side, she is 96 so I do more! I don't think she is capable of coming and lifting me off the floor! You know it is very pleasant. We have thought about moving and downsizing because the price of the property, we would have to spend as much again and wouldn't have this quality of life really. So, when needs be, we will get a stair lift! [laughs].

DN: So you definitely don't see yourself moving from here then, you are content?

Erm…unless something drastic would happen, you know. From a tragic point of view. My wife is on the road all the time, if something like that happened, you couldn't live here anymore, and vice versa for her, as well I'm sure.

DN: Do you think there is any negatives to living here, with regards to your health?

Erm, no. I can't say there are any negatives in the sense. Explain what you think negative means.

DN: For instance, you said at the beginning about having to travel to Lincoln for chemotherapy. So something like that, treatment closer to you, accessibility?

Yeah. Yeah. It would, yes it would. I had a bad experience in Boston, really bad experience and I would never go back there again.

DN: Was this to do with your cancer care?

I lost a tube, it popped out. And they didn't know what to do about it. I had nothing to eat for four days and nothing to drink. They just left me in the side room. They kept calling the procedure that I had a PEG (Percutaneous Endoscopic Gastronomy). No, it's a RIG (Radiologically Inserted Gastrostomy). Erm, so I had to wait over the weekend, and into the following Thursday until a radiographer could come and do it, in Boston. At that time, I was pretty high on morphine. Well, fentanyl, actually at that stage. And oramorph, cocodamol, a

lot of pain. I was in a lot of pain. Three weeks after I had finished the radiotherapy and the chemo, and they did say, you think it's bad now, I'm afraid you are going to go through hell for the next month or so, and I surely did. But, I was treated fairly disrespectfully, I feel there. Plus, the fact that I was out of it. Anyway, I had all that done, came back. And this is just an aside really, I was upstairs in bed, feeding tube in and the machine going. And my old dog came and sat at the end of the bed. I thought, I'm not having this anymore! So the next day, I thought ill go back to the syringe, get rid of this and put up with it. And I think two weeks later it dropped out anyway. So I had no choice. Get on to food! So a lot of ice cream, a lot of custard soups, it tasted horrible but it kept me going.

DN: Do you have any issues with fatigue or tiredness, things like that?

Yeah. As a result, that's where this underactive thyroid was diagnosed by my GP. But, I'm OK. I sleep well. I go to bed early, I must confess. Sometimes I can be in bed at 8 o'clock and not get up until 6. And out like a light. Which I quite enjoy really.

DN: And do you have any needs or anything at the minute that you think aren't being met?

No.

DN: So you feel quite well looked after, in terms of networks, support?

In terms of networks, no because I don't have a big social network. I have a few friends who I have been friends with for forty years. I'm not the sort of person that goes out and seeks new acquaintances or whatever. And since they pulled the pub down over the road! [Laughs] There would be no chance of that. I go to a wood turners club.

DN: And where is that?

That's just down the road. But I am the youngest one then. Senior citizens! [Laughs]. I'm a senior citizen I suppose really. Yeah, yeah. It's difficult for me to say, I don't feel looked

after, cause I know that should I need it the support is going to be there. As for Macmillan, there needs to be more people that work not in palliative care. Because that is the only team that is based here, there are three of them and they are all palliative care. And at one point, Liz came a few times because I wasn't eating, I was refusing to, you know, being very difficult. And she just read me the riot act really, get a grip.

DN: Right. And that worked then?

Yeah, I got a grip. She was very good about it but she said look what it is doing to your wide, look what it is doing to your kids. They want to help and support you. But if you refuse, it just makes the situation worse. So yeah, I got a grip.

DN: Well you mentioned earlier about palliative care, and not enough support for men, is there anything else you think that people could benefit from locally or even at a national level. For people who have been through something like yourself?

I think more of a focus on men. It is something that you read, even on the Macmillan website there are lots and lots of references to it. Because I think there is a lot emphasis on women and cancer, there always has been. Men don't talk about cancer do they. And I think opportunities to share with men would have been better for that survivors group. That should have been divided separately, you know, men and women, really. You know, I could have seen myself, in that role, as a facilitator in that kind of group, for men. But not doing the mindfulness bit! [Laughs].

DN: So is that something you would be interested in then?

That's something I am interested in yeah.

DN: And have you spoke to Macmillan about getting involved?

I did yeah. Erm they never got back to me.

DN: Do you know who you spoke to?

No. It was via the website. A chat situation not a one to one voice thing. But there is nothing round here for volunteering. Where there are volunteering opportunities, they are miles away, absolutely miles away.

DN: I know they do lots of stuff in and around Lincoln but the county sometimes can be very Lincoln centric isn't it?

It is, it is. I mean there are a couple of hospices in the area and they do offer support but I don't want a head massage, that sort of thing. I want a challenge; I want to be challenged.

DN: OK. So something a bit more simulating?

Yeah. Yeah.

DN: Is there anything else we could benefit from doing, or changing?

I think particularly for people living in rural areas, the phasing of chemo, radiation because that is a huge, well it was, a huge issue. For the whole family, it was. The timings are crazy. There is no continuity, you are not on a rota. And that was an issue. I cant really think of anything else, other than something to bring men together. Opportunities to share experiences both treatment and after treatment, and projects that you might want to get involved in you know.

DN: OK. I think we have covered everything. Is there anything you would like to add about your experiences, anything we have left out?

Erm, no I don't think so, we are done.

INTERVIEW ENDS